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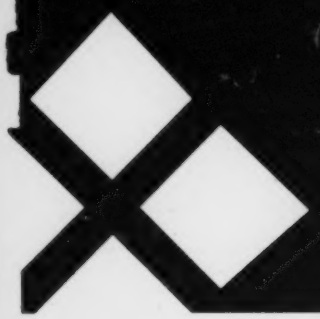
ABSTRACT

This document provides information about the 1990-93 overseas fellowships of the International Exchange of Experts and Information in Rehabilitation (IEEIR), based on project summaries and reports from fellows and hosts. It begins with an interim report from an IEEIR fellow who traveled to Australia and a letter from a host in New Zealand. The interim report described the Illawarra Regional Health Service (New South Wales), and the IEEIR fellow's experiences during his visit. The letter from a New Zealand host welcomed the possibilities for a U.S. and New Zealand collaboration that will bring new ideas and directions in working with people with disabilities. Summaries of the 1990-1993 fellowships are then offered, in the following topic areas: technology, medical rehabilitation and research, special education/rehabilitation education, community-based rehabilitation programs and concepts, advocacy, sensory disabilities, vocational services/employment issues, mental health/psychosocial, attitudes and cultural biases, and developmental disabilities. The fellowships involved projects in Canada, Hong Kong, Thailand, England, and Kenya, among other countries. An article reprint is presented which captures the spirit of cross-cultural collaboration, "Developing Mutual Understanding between Western and Non-Western Cultures through Collaborative Research" by Judy Kuglemass and Kusdwiartri Setiono. The document also includes a section on what has been learned by carrying out fellowships over the last 15 years, based on a survey of 60 IEEIR fellowship participants. Survey findings are summarized in sections on professional profiles of participants, professional outcomes of experiences, and professional international resources, respectively. The document concludes with a list of fellows, a list of advisory committee and peer review panel members, and a list of monographs available from IEEIR. (JDD)



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IEEIR

Monograph #54

ED 375 582

Developing Awareness of Disability in the World

Looking at Issues Relevant to Disability in Asia, the Pacific, and Africa Through the Eyes of U.S. Fellows

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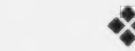

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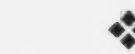

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1990 - 1993 Fellowship Study Reports

❖ Technology

Effectiveness of Assistive Alerting Devices for the Hearing Impaired; E. Nober (Australia), 1993.

A Cross-cultural Model for Appropriate Technology Prosthetics; T. Staats (India), 1993.

Sociopolitical Perspectives Affecting Acceptance of Rehabilitation Technology (Australia); A. Cronin, M.A., OTR, 1990.

❖ Medical and Rehabilitation Research

Clinical and Electrodiagnostic Assessment of Leprous Neuropathy; T. Brown, M.D. (Thailand), 1992.

Delivery of Psychological Services to People with Spinal Cord Injury in Australia; S. Ducharme, 1993.

Continuous Passive Motion: Two New Approaches to Reducing Low Back Pain and Disability. R. Hazard (US and NZ), 1993.

Strategies for Enhancing Communication and Interactions Between Physicians and Persons with Physical Illnesses and Disabilities; M. Backman (NZ), 1991.

Awareness of Behavioral Limitations after Traumatic Brain Injury: A Cross-cultural Study of New Zealand Maori and Non-Maori; G. Prigatano, 1991.

Traumatic Brain Injury (Ma'i Ulu) in Amerika Samoa: Rehabilitation Needs and Services; G. Wallace, 1991.

❖ Special Education/Rehab Education

Special Education in Rural and Isolated Areas of Northern Thailand: Developing a Collaborative Model;
J. and S. Tewksbury, M.A., 1993.

An Application of Australian Distance-education Models to Rehabilitation Education Curricula in the United States; C. Schiro-Geist, 1993.

Innovative Ideas in Educational, Medical, and Social Care of Disabled Children in Greece, Turkey, Africa, India and Southeast Asia; C. Butler, Ph.D., 1992.

International Exchange in Development of Rehabilitation-related Education: The United States and Malaysia; J. Armstrong, 1992.

Study Seminar and Conference on Educational Technology in the US and Japan - Implications for Special Education; B. Rankin, A. Haring, 1992.

Disability in Kunming, China: An Overview of Special Education and Rehabilitation Programs; M. Condon, Ed.D., 1990.

❖ Developmental Disabilities

Pilot Survey of Mentally Handicapped Children and Youth in India - Prevalence and Extent of Disability; Care and Services Received and/or Needed; H. Wallace, M.D., M.P.H., 1991.

Development and Disability in Zimbabwe: Voices from the Periphery; J. Charlton, 1992. (order monograph #53)

The Effect of Privatization on the Delivery of Mental Retardation Services in Israel; M. Kivitz, 1992.

Dreams for Desirable Futures for People with Developmental Disabilities: A Comparison of Australia and the US;
J. Strully, 1992.

❖ Vocational Services/Employment Issues

Vocational Rehabilitation Development in Hong Kong: A Cross-cultural Perspective; C. Lam, 1990.

Disability Management & Work Return Transition Programs for Injured Workers: A Study of Exemplary Australian Programs, Policies and Services; D. Shrey, 1993.

Multi-disciplinary Rehabilitation of People with Disabilities: A Study of the Accident Compensation Corporation of New Zealand Rehabilitation Team Approach; C. Guenthner, 1992.

❖ Mental Health/Psychosocial

Psychiatric Rehabilitation in Kenya: Applications to the Rural US; P. Ginsberg, Ph.D., 1992

Development of Integrated Healing Model to Address the Mental Health Crisis Among Khmers ;
S. Brown, Ed.D., L. Gerber, Ph.D., 1991

An Examination of the Applicability of Morita Therapy to the Psychosocial Rehabilitation of Persons with Psychiatric Disabilities; I. Rutman (Japan), 1993.

An Exchange of Psychiatric Rehabilitation Knowledge & Research Between China & the USA; R. Liberman, 1991.

Rehabilitation Services in New Zealand for People with Chronic Mental Illness; F. Silvestri, 1992.

Exploring the Severity of Post Traumatic Stress Disorder and Learning More Efficient Ways of Treating Chronic Trauma in the Gaza Strip and the United States; J. Raasoch, C. Sedor, B. Jordan, 1992.

Health Professionals, Families, and Long-term Mental Illness: A Chinese Traditional Medicine Collaboration Model; S. Govig, 1992.

❖ Community-based Rehabilitation Programs and Concepts

Parent Advocacy and Family-centered Care for Children with Disabilities and Their Families — Linking North American Experiences with Eastern European Initiatives; W. C. Cooley, M.D., P. Arango (Czechoslovakia), 1993.

Analysis of Policy Designed to Promote Accessibility of Public Accommodations and Services Housing and Transportation in New Zealand; M. Mathews, Ph.D., 1990.

Improving the Effectiveness of Consumer Participation: Community Based Rehabilitation (CBR) Schemes as a Model for Consumer Responsive Disability Support Systems;
A. Enders (India), 1993.

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❖ Preface

In this final publication of the 1990 - 1993 IEEIR project period you will find an array of information about the IEEIR overseas fellowships, including some interesting ideas and collaborations that have come out of the project from fellows and hosts.

For example, an interim report, requested of IEEIR fellows who typically spend four weeks abroad carrying out a fellowship study visit, is intended to serve as a way of reflecting on and organizing one's experience about halfway through the fellowship. Fellows' reflections and subsequent interim reports take different forms. Stanley Ducharme's is quite recent, informative, and should give you a sense of what an IEEIR fellowship experience looks and feels like as it is being experienced. Nancy Eldredge's is very recent, personal and quite unique.

Bob Gregory, the author of a detailed host-follow-up letter has been a highly involved host over the past ten years. His hosting of IEEIR fellows has enriched the experience of the fellows, and, as you can see by reading his piece, as well as Dennis Harper's piece, also enriches *him*, and others' experiences in New Zealand.

The array of abstracts, summaries, overviews, and reports of IEEIR 1990-1993 fellows shared in this publication are intended to provide the reader with a taste of each fellowship experience reported on. Whether or or not it is an abstract or a report has no bearing on the substance of the individual fellowship experience or the actual report of that experience which, in most cases, is available and can be requested from the IEEIR.

Although the thirty or so pieces relating directly to the IEEIR fellowship studies are "categorized" under one of seven headings for the convenience of the reader, it is understood that no category is absolute. For example, two pieces which appear under *Special Education* could also appear under *Community Based Rehabilitation Services and Concepts* as could at least one falling under *Mental Health Issues*.

A particularly interesting "interim report" (i.e. a report written and sent in to the IEEIR approximately halfway through the study-visit) came in after we had already decided to "feature" another illustrational interim report. Since we wished to include this additional interim report in the publication because of its particular cultural value, it has been inserted under *Sensory Disabilities*. Because it relates to a study done on hearing impairment in Australia (see Nancy Eldredge's report).

Dissemination of Mental Health Fellowships

Excerpts from a report by Polly Ginsberg from a presentation resulting from her IEEIR fellowship study on mental health issues in urban and rural Kenya and Stewart Govig's "poster session" relevant to his study in China are being presented as examples of ways to disseminate ideas from abroad.

Other 1990-1993 fellowships relevant to mental health featured in this publication are: ❖ one carried out by Sharan Brown and Lane Gerber in Cambodia: *Development of an Integrated Healing Model to Address the Mental Health Crisis Among Khmers*, ❖ information about Irvin Rutman's recent trip to Japan to study Morita Therapy, ❖ John Raasoch and Chris Sedor's examination of PTSD in the Gaza Strip, ❖ excerpts from Fran Silvestri's study of mental health rehabilitation innovations in New Zealand, ❖ excerpts from Robert Lieberman's experiences in China.

Fellowship Survey Report

In addition to various write-ups by and about the fellows and their overseas studies, this publication includes a section on what has been learned by carrying out fellowships over the fifteen years that the IEEIR has been funded.

So many people have had an interest in the project that we feel they would be interested in looking in on the results of this follow-up survey that was conducted during spring of 1993 with the assistance of Susan Frankel of UNH. Of particular interest is the way that most fellows experience overseas professional *learning* visits as enduring professional and personal experiences that offer them opportunities for reflection and reevaluation of their culture-based assumptions. The influence that *they* then have on their junior colleagues and on consumers, both in practice and through education has a ripple effect influencing how we carry out effective rehabilitation education, service and policy and planning.

Benefits of Cross-cultural Collaboration

Because the IEEIR has not sponsored exchanges in Europe or Canada since 1987, the fellowships have been conducted in some countries where at first glance it might be difficult to ascertain what we in the U.S. can learn. Therefore, it has been important for fellowship applicants to really think about and plan for what can be learned from other cultures. It has been an effort well placed.

In the process of truly sharing and respecting each other's work, experiences and cultural differences, true cross-cultural and cross-national collaboration can occur. To show this, we have chosen to repeat in this publication an article which was published almost two years ago in *Interchange* which captures the spirit of this cross-cultural collaboration we try to encourage in this project and which we know has influenced several of the 1990 - 1993 recipients of IEEIR fellowship awards (see *Developing Mutual Understanding Between Western and Non-Western Cultures Through Collaborative Research*, by Judy Kugelmass & Kusdwiartri Setiono).

We would hope and expect that in various ways, people who have been touched by this project and its philosophy will continue to participate in and talk and write about the benefits (as well as the pitfalls) of cross-cultural, cross-national exchange of ideas.

Diane E. Woods
Project Director
September 1993

❖ Interim Reflections and Collaborative Possibilities

❖ An IEEIR Fellow's Reflections Halfway Through: An Interim Report*

From a Letter to the IEEIR from Stanley Ducharme, Ph.D., Director, Rehab Medicine Boston University School of Medicine

"Greetings from Australia. I am pleased to inform you that after what seemed like an endless plane trip that I've made it here and am now almost two weeks into my fellowship project. At this point, my study visit is moving along well although I have come to realize that certain changes in my original plans may have to be made. Most notably, it has been necessary for me to examine a broader group of disabilities than spinal cord injury alone. However, I feel that this has only added to my experience rather than detracted from it. This letter will serve as my interim report to the World Rehabilitation Fund.

"I arrived in Australia on March 22, 1993 after long flights on American Airlines and Air New Zealand. Fortunately, I was able to break up my long travel time with a psychologist colleague in Los Angeles and a week-end stay in Rarotonga of the Cook Islands. While in the Cook Islands, I was able to get a visit and tour of the local hospital after discussing the purpose of my visit with people at the local car rental agency. The hospital itself was a small facility with minium resources that was located close to the main town on the island. Although English is the language of the Cook Islands, the local dialect was difficult to understand and questions often added more confusion than clarity. Nevertheless, it was a fascinating introduction to the health system of the Pacific Region. It was also exciting to know that my study visit was finally underway after many months of planning and a delay from my original departure date.

"I was met at the airport by my study host, Dr. Lynette Lee and the business manager of the Illawarra Regional Health Service. It was about a two hour drive to reach the town of Kiama, south of Sydney, where I was to be the house guest of my host and her family. Over these past two weeks, I've been fortunate enough to be the guest of Dr. Lee, her husband Dr. McDonald and their two children, Patrick and Robert. They have been exceptionally generous during my stay setting up a barbecue with local psychologists from the University of Wollongong, touring me around the countryside and giving me plenty of information regarding the cultural aspects of life in Australia. In addition, Dr. Lee has worked hard in organizing various components of my study visit such as lectures, workshops and meetings at a number of community agencies, hospitals and the local University. Being the guest of an Australian family has further enriched my visit by exposing me to the day to day life of Australians and integrating me into the family unit. It has also allowed me long hours during the evenings to be able to process my perceptions of the rehabilitation process and to have more in-depth discussions of my experiences.

Continued on page 49

** also see page 25 for another interim report*

❖ The Possibilities for U.S. and New Zealand Collaboration: A Host's Perspective

From a Letter from Robert J. Gregory, Senior Lecturer, Department of Psychology Massey University, Palmerstown North, NZ

"Regarding **Dennis Harper's** visit to New Zealand under International Exchange of Experts and Information in Rehabilitation (IEEIR) sponsorship, *(Social Preferences of Maori Children Towards Visible Physical Impairments)*, I would like to offer some observations and ideas, and thank you for the opportunity to work with Dr. Harper.

"My initial observation is to record for you the range and high quality of tasks completed - a record of performance:

Without the extensive preliminary contacts, and without the background of working over the phone, via E-Mail, by letter, and through exchanges of reports, this project would have not been as successful.

"1) Four individual seminars (two hours each) for faculty and advanced graduate students, mainly in the Department of Psychology and advertised as open to the campus at large.

"2) Seminar (two hours) with Clinical Psychology graduate students (class conducted by Cheryl Woolley) in which a case presentation and a review of advanced psychodiagnostics were offered.

"3) Seminar (two hours) with Advanced Rehabilitation Studies students in my class in which Dennis presented ideas and we talked about rehabilitation psychology and attitudes.

"4) Individual meetings with numerous faculty and advanced graduate students in rehabilitation studies, psychology, and clinical psychology.

"5) Presentation to local special education teachers at the Palmerstown North Teachers' College on the research and on strategies that teachers could use in classrooms.

"6) Presentation and subsequent discussion and exchange of information, ideas and feelings about children with disabilities in New Zealand with local school psychologists. The meeting took place in the local school system.

Continued on next page

"7) Co-presentation of attitudes toward disability research with Mihi Ratima, Researcher at the Maori Health Research group's initial special seminar series sponsored by the Department of Maori Studies. Among participants were Maori health professionals from several areas of New Zealand.

"8) Presented information about the research project on attitudes to disability among Maori children through an interview format conducted by Ms. Kim Hill for the New Zealand National Radio program "Morning Report" on 30 March 1993. A tape was made of the presentation and both Dennis and I will retain a copy for future use in teaching.

"9) Completed the data collection of the research proposed and funded by the World Rehabilitation Fund (IEEIR), including interviews of well over 125 children. The data collected, with only preliminary analyses conducted so far, appear to be of interest and value, both in terms of research interests on attitudes generally, and specific interests for Maori children in New Zealand.

"10) Made plans to co-direct an Honors Thesis of Mr. Steve Rowsell of the Psychology Department of Massey University with co-supervision by Malcolm Johnson of the department. The research will extend the study of attitudes toward physical disability of New Zealand children.

"11) Made plans to develop, with myself, Dennis, and others, an "International Issues Course on Disability," via E-Mail, for our advanced students, in several countries for 1994.

"12) The third seminar presented by Dr. Harper in the Department of Psychology was based on his paper titled "New Paradigms in Research and Practice in Childhood Rehabilitation." This paper led me to state to the audience following the seminar that I quote (as best I can from memory): "Dennis, you have taken us from the stage of 'Give a boy a hammer and he will hammer everything in sight,' levels of research to 'Try a range of options and choices with the many tools available.' further on to 'Try gaining the big picture and manage the information as with a camera,' to 'Let's also include the process as with a video,' to 'We have recently opened the doors to new paradigms in which we can think and carry out our research with the power of computers and virtual reality'." Truly this was a special paper, and I am proud that it will appear as an Occasional Paper in the Department of Psychology series.

"13) Shared ideas and began to draft a paper on cultural issues for researchers in the disability arena, specifically on the roles of "insiders and outsiders" who team up to conduct research.

"14) Anticipate publication of the data gathered on Maori children's attitudes towards physical disability following data analysis.

"15) Anticipate publication of the data that will be gathered by Steve Rowsell and Malcolm Johnson on Maori children's attitudes towards physical disability.

"16) Stimulated me to write up a report on the status of rehabilitation psychology efforts in New Zealand, with Jodie Batten, advanced graduate student. This paper may be published in the Newsletter of Division 22 (APA).

"In the way of ideas, I would like to comment that the use of E-Mail made a major difference for both of us, in preparation, for Dennis in maintaining contact with researchers back in the United States, and I anticipate, for both of us in writing up results and continuing contact in the future.

"Without the extensive preliminary contacts, and without the background of working over the phone, via E-Mail, by letter, and through exchanges of reports, this project would have not been as successful. IEEIR guidance in enabling us to establish early and continuing contact.

"For me personally and professionally, this visit has been remarkably productive, meaningful and successful. My students have benefited in a wide variety of ways. Also, I am pleased that my department, the Department of Maori Studies, the University, and the community have also gained. I anticipate that the benefits of the research data, yet to be fully analyzed, will also bring us new ideas and directions in our work with people with disabilities."

❖ *1990 - 1993 Fellowship Summaries*

❖ Technology

❖ Effectiveness of Assistive Alerting Devices for the Hearing Impaired in Australia

E. Harris Nober, Ph.D., School of Public Health, University of Massachusetts

Hosting E. Harris Nober in June 1993 was Dr. Norman Erber, Communications Disorders/Health Sciences at La Trobe University, Bundoora Campus.

The purpose of Nober's study was to collaborate with a variety of resources: developers of a popular cochlear implant device; directors of schools for the deaf; mainstream programs for the hearing impaired, university researchers, engineers and regulatory officials regarding assistive safety device signals for the hearing impaired and the hearing impaired elderly and to share his expertise with these groups.

Dr. Nober's experimental research on audible and visual smoke detector safety alarm effectiveness for the general public, the severely hearing impaired, the mentally impaired and the elderly has been his main research focus for over a decade. A series of experiments, "Waking Effectiveness of Household Smoke and Fire Detection Devices", conducted at the University of Massachusetts, Amherst, established the baseline data now used in the United States and England.

❖ A Cross-cultural Model For Appropriate Technology Prosthetics: The Jaipur Foot Revisited

Dr. Timothy B. Staats, ED.D., C.P., Director, UCLA Prosthetics Research Project, Rehabilitation Center, Los Angeles, California

Introduction

This IEEIR Fellowship study related to choices of appropriate prosthetics and orthotic technology in the developing world and cross-cultural implications for the United States. The study involved a visit by the fellow with Dr. P.K. Sethi, a leading expert on appropriate technology prosthetics, in Jaipur, in **Rajasthan, India**. The thrust of the visit was to discuss field research findings collected by the fellow and to resolve inconsistencies in those findings with published literature. The summary report of discussions provides insights into the complicated mosaic of prosthetics and orthotics technology seen in the world.

Background for the Fellowship

Dr. Timothy Staats is an American certified prosthetist and is the Director of prosthetics orthotics education and research at the University of California at Los Angeles, California. During the past ten years, in additional to clinical and educational responsibilities, he has conducted informal field research dealing with use and choices of prosthetics and orthotics technology as part of various international consulting assignments for governmental and nongovernmental agencies. These assignments have included assessments of need for humanitarian assistance for amputees and other physically disabled people in Lebanon, Ethiopia, Cambodia, Laos, Vietnam, Armenia, and the Occupied Territories of Israel (Gaza Strip and the West Bank). In addition to these humanitarian assignments, additional work for the purpose of organizing and conducting prosthetics training seminars for prosthetists in Mexico, Canada, Australia, Spain, Argentina, Russia, Sweden, England, Scotland, Norway, Denmark, El Salvador and Cuba provided the opportunity to study prosthetics service models in a variety of cultures to gather photographs related to prosthetics techniques and technology in both workshop and living conditions.

Dr. Staats examining amputees wearing Jaipur limbs at Som Hospital, Jaipur

A formal request was made to the IEEIR for this fellowship study trip to share with Dr. Sethi samples of the collected data and to have mutual discussions about perceptions of appropriate technology for prosthetics and orthotic. The discussions proved to be as philosophical as scientific in nature, and initial plans for visit for 4 days in Jaipur were soon extended to 8 days.

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The IEEIR fellowship to India accomplished the following activities:

❖ Travel from Delhi to Jaipur viewing generally urban and rural living, working, and travel conditions. Examples of primary cause of amputations in India were seen in numerous traffic accidents enroute.

❖ Intensive discussions were arranged on appropriate technology, prosthetics and rehabilitation between Dr. T. Staats and Dr. PK Sethi, Chief of Orthopedic Surgery at S. Durlabghi Memorial Hospital (SDM) in Jaipur India. There was sharing of ideas and knowledge from experiences in many cultural and social conditions.

Choices of appropriate technology for amputees and the physically disabled person in the developing world requires a thorough understanding of the living conditions, culture, and working environment to design and build prosthetics and orthotics assistive devices that will suit the needs of the individual.

❖ In Jaipur, technology transfer by Dr. Staats to the host institution included four days of lectures and demonstrations on prosthetics technique and technology with professional staff at a prosthetics/orthotics workshop at SDM Hospital. Topics included UCLA total surface bearing below the knee prosthetics; Ischial containment above the knee prosthetics; and UCBL shoe insert orthotics.

❖ In Jaipur many technology transfer discussions took place regarding SDM staff intention of expanding polio orthotics efforts. Expertise on orthotics designs and solving fabrication problems were shared.

❖ In Jaipur, a review of patients fitted with Jaipur-style below knee prostheses; polio bracing patients; and India style hand powered rickshaws were conducted.

❖ Travel from Jaipur to Agra and New Delhi by private hired car permitted a slower paced viewing of urban and rural living, working, and travel conditions and observations of how disabled citizens are integrated into society. The fellow hired a retired school teacher as a guide and arranged a special tour of poorest areas of Delhi through four separate cultures, to see firsthand those areas where amputees, and other severely disabled people congregate to live, beg, and work.

General Findings and Impressions:

Choices of appropriate technology for amputees and the physically disabled person in the developing world requires a thorough understanding of the living conditions, culture, and working environment to design and build prosthetics and orthotics assistive devices that will suit the needs of the individual. One should not have preconceived ideas about what the living conditions, culture, and working environments will be in any country, or even within a region of a country due to a plethora of variations. The political status and stability in a country may greatly influence the selection of prosthetics and orthotics technology. That is, whether a country is at peace, at war, or in a post-war period, the strength and organization of the government infrastructure can affect the selection of technological choices. The form of government may also contribute to the quality and quantity of services provided. There is a lack of understanding of prosthetics and orthotics technological choices for the developing world and post-war world which is evidenced by inappropriate selections of prosthetics and orthotics techniques and technology; and by unrealistic expectations and guidelines by humanitarian funding agencies.

There is a difference between prosthetics-orthotics care delivery in poor countries that are at peace as opposed to poor countries at war. War zone prosthetics and orthotics may be considered an acute situation whereas a country at peace may be considered to have a chronic problem with disability. In the long term both situations are chronic but the public awareness to offer assistance is heightened and made acute by mass-media coverage of war. It may be easier to raise money for acute situations and relief agencies are more likely to come to high profile problem areas than long term chronic areas. There is an world-wide shortage of trained prosthetics-orthotics instructors and trained prosthetists and orthotists. In the developing world there is a need for prosthetist-orthotists with a broad range of skills with multiple technologies so that whatever prosthetics technology is available may be taught and utilized. This requires "flexible response tactics" to prosthetics and orthotics rehabilitation. It may also require "rehabilitation triage tactics" as more difficult cases may be deferred and higher volume or less difficult cases handled. The skill of the available prosthetics-orthotics work force will dictate the types of problems that can be addressed.

Too much emphasis is placed on the volume of prostheses and orthoses delivered rather than the usefulness to the disabled person who must live and work using the device.

There is a need for prosthetics-orthotics educational materials suited to use in poor countries by volunteer prosthetic-orthotics instructors who may not have teaching experience and may be teaching individuals with marginal education credentials. There is a similar need for educational materials in the United States as no new training materials have been written in decades. There is a need to conduct research on prostheses and orthoses at the point of use rather than the point of delivery. Too much emphasis is placed on the volume of prostheses and orthoses delivered rather than the usefulness to the disabled person who must live and work using the device.

Summary

The final report of this IEEIR Fellowship study uses country examples and photographs from Dr. Staats international travel to illustrate and elaborate each of these points.

❖ Medical Rehabilitation and Research

❖ Clinical Assessment of Early Leprous Neuropathy with Electrophysiological Correlation

Ted Brown, M.D., Chief Resident, Department of Rehabilitation Medicine, University of Washington

Since the 13th Century, nerve involvement has been a recognized and universal feature of leprosy. Sequelae of peripheral nerve damage include loss of function, contractures, digital resorption (shortening of the digits), neuropathic ulcers and joints, osteomyelitis and ultimately, amputation. Ted Brown's IEEIR project was to study nerve damage associated with leprosy. In late 1992 he spent six weeks performing physical and electrophysiological testing of patients with newly diagnosed leprosy at McKean Rehabilitation Center and Chiang Mai University in **Northern Thailand**.

The results identified common clinical and electrodiagnostic manifestations of nerve damage and also identified duration of illness as an important predictor of severity of neuropathy. This gives credence to ongoing efforts to achieve early diagnosis in the Third World. The results have or will be presented at three national and one international conference and have been submitted for publication.

Since returning from his IEEIR fellowship, Ted Brown has received a Heiser fellowship to continue leprosy research. He has also accepted a staff position at McKean Rehabilitation Center in Chiang Mai, Thailand where he will be a rehabilitation specialist. The IEEIR fellowship has played a significant role in determining his career path and making the neuronal manifestations of leprosy more familiar to American health professionals.

❖ Continuous Passive Motion (CPM), Two New Approaches to Reducing Low Back Pain and Disability

Rowland Gibson Hazard, M.D., Director of Rehabilitation Services, Spine Institute of New England

In February 1993, Dr. Rowland Hazard received an IEEIR fellowship to exchange ideas in the area of continuous passive lumbar spinal motion with Robin McKenzie in **New Zealand**. Mr. McKenzie is a world-reknown expert in the area of self-care exercises for low back pain, and heads the McKenzie Institute International, with teaching faculties throughout the world.

Currently low back pain is the most disabling musculoskeletal condition in the United States. Over 70% of the population at some point experiences significant disability from low back pain, and current costs for associated medical care, work loss and compensation exceed $50 billion annually. Multiple preventative and therapeutic strategies have evolved over the years in the United States and elsewhere, but the "epidemic" of occupational low back pain continues unchecked. Recently, researchers in the United States and New Zealand have independently developed techniques for preventing and reducing low back pain utilizing continuous passive motion or CPM.

CPM has been used for many years to increase joint stability and ligament and tendon function in peripheral joints following major surgery. It is reasonable to expect that continuous passive motion in the lumbar spine might have similar tissue benefits in addition to improved intervertebral disc physiology. From an epidemiologic perspective, a potential benefit of CPM is suggested by the fact that occupational low back pain has a well documented association with sedentary work. One biomechanical strategy against sedentary low back pain has been lumbar support, usually with some form of cushioning. The CPM device developed by Hazard and Reinecke takes advantage of this lumbar support concept by providing cycles of gradually increasing and decreasing lumbar support.

Hazard and Reinecke have recently researched two critical features of continuous passive motion in seated individuals. First, when people without clinical histories of low back pain used their device (the Back Cycler CPM) at individually selected pressure levels, significantly greater lumbar lordotic motion occurred than when the CPM device was in place but not operating. In order to measure this lordotic motion in a seated individual, a new device, the Lordosimeter was developed within the Vermont Rehabilitation Engineering Center by Reinecke, et al. Second, patients with chronic stable low back pain who drove more than two hours per day reported higher levels of comfort and lower levels of stiffness and fatigue when the device was operating than when it was not.

The purpose of this fellowship was to allow Hazard and McKenzie to observe together clinical applications of this CPM approach as well as with the mechanical Repex device which McKenzie had been using as a therapeutic approach to acute and chronic low back pain. Both researchers realized that measurement of repetitive lordotic spinal motion might be key to further research in this area.

Measurement of Lumbar Lordosis

During this fellowship, Hazard introduced the concept of continuous lordosis measurement using the Lordosimeter device for clinical applications. In Mr. McKenzie's clinic in New Zealand it became clear that a less technical and time consuming measurement technique was needed for clinical use. Therefore, three other methods for lordosis measurement were evaluated: a flexible ruler, dual inclinometers, and skin attraction. A formal study was carried out to assess the interrater reliability of each technique in measuring prone lordotic movement of the lumbar

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spine. This evaluation revealed the superiority of the skin attraction technique, and a manuscript of this study has been submitted for publication in the New Zealand Journal of Physical Therapy. This measurement research suggests that skin attraction can be used simply and accurately in future studies of lordotic treatment techniques.

CPM and Seating: The Back Cycler CPM

The fellowship included car driving tests of the Back Cycler CPM device, during which a number of insights were developed. First, the initial physical sensation of movement provided by the device may be somewhat uncomfortable for people who are not accustomed to sitting with lordosis. This observation was made by Mr. McKenzie through his own extensive experience with static lumbar supports. Apparently, patients with long-standing back pain can be sensitive to this initial discomfort but eventually find that lumbar support allows them greater comfort during prolonged seating. This observation fits with the second finding that within minutes of turning on the device, its cyclic inflation and deflation are not only not distracting, but may not be evident to the user as he or she attends to the task of motor vehicle driving. The action of the device is easily noticed if attended to, however. The most dramatic results of using the device are enhancement of comfort over long periods of sitting (usually greater than one half hour) and the absence of low back stiffness which commonly occurs after prolonged sitting. It is assumed that this latter finding has some pathophysiologic basis associated with the lumbar spinal movement measured in previous research. If repetitive lordotic CPM does discourage posterior migration of the nucleus pulposus, ligamentous creep, and muscular fatigue, the Back Cycler CPM may not only be able to make prolonged sitting more comfortable, but to reduce the low back injuries which occur with lifting and other trunk stresses immediately following prolonged sitting. Mr. McKenzie had some very helpful suggestions particularly in the area of converting the Back Cycler CPM into an aid for treating patients with back pain either in the physical therapy or home setting.

Mr. McKenzie and Dr. Hazard have subsequently written an article regarding CPM for low back problems with Dr. Vert Mooney, and publication is anticipated in the *Journal of Musculoskeletal Medicine*. It is hoped that the findings and insights provided by this fellowship will benefit future research and development efforts in the Vermont Rehabilitation Engineering Center at the University of Vermont and in Ergomedics, Inc., Winooski, Vermont, the industrial developer of low back CPM. Mr. McKenzie will continue to evaluate and disseminate information about CPM through his teaching institute.

❖ *Strategies for Enhancing Communication and Interactions between Physicians and Persons with Physical Illnesses and Disabilities*

Margaret E. Backman, Ph.D. Psychologist

Background

With the advent of sophisticated medical treatments, the psychological needs of those with physical illnesses and disabilities are often minimized. The purpose of Backman's study-visit was to identify methods and services that enable physicians to be more sensitive to the psychological needs of their patients.

As part of the project, interviews were conducted with medical staff, nurses, occupational therapists, patients/consumers, and mental health professionals in **New Zealand, Australia, the Republic of Fiji and The Cook Islands (Rarotonga)**. The research questions were: ❖ What are physicians' attitudes toward the psychological needs of their patients; ❖ What training is available to medical students and practitioners to educate them regarding the emotional needs and reactions of patients; ❖ What role do mental health professionals play in the treatment of disabled clients and medically ill patients; ❖ How do consumers perceive their care, and how do they influence their care in terms of its meeting their psychological needs; ❖ What are the issues involved in cross-cultural communication when physician and patient are from different cultures.

Implications for the United States

The findings of this project have important implications in the United States in many areas: training programs, consumer advocacy and support groups, rehabilitation agencies, hospitals, continuing education of physicians and mental health practitioners, and research.

In all the countries visited, physicians and patients expressed a need for psychological support for coping with physical illnesses and disabilities. However, physicians complained of being too busy to attend to patients' psychological needs themselves, and they mentioned the dearth of well-trained mental health professionals in their countries. In the United States we do have a resource of such professionals; however, their services are incorporated into the rehabilitation field to a much greater extent than into the medical field.

The Mental Health Professional as Part of the Treatment Team

As the study-visit found, mental health professionals need to inform physicians about the various services that they can provide, and physicians in turn need to learn how to work as a team with these professionals. Such cooperation would not only relieve physicians of the burden of having to spend more time with patients, but would also assure patients that their psychological needs are being met by those with specialized training in mental health.

Physician Education, Training and Research

The practical importance of good patient-doctor communication should be stressed in training programs and in continuing education programs for physicians. In the United States more and more medical schools have been introducing courses in the behavioral and social sciences. The findings of this study-project support the

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need for positive role models, i.e., established physicians and mental health professionals, who reinforce in the applied clinical settings the value of psychological support.

Research programs should be developed to identify 1) unmet needs in patient-doctor communication and 2) the most effective utilization of mental health resources in the treatment of medical illness and disability. Such research is of increasing importance in light of the movement toward national health insurance and HMO's. Third party payers, i.e., insurance companies and the government, need to be made aware of the importance of mental health care in the treatment of patients with chronic illnesses and disabilities—not only for quality of care but for reduction of costs.

Issues in Cross-Cultural Communication

This study-visit has revealed the importance of sensitivity to cultural differences for effective communication and medical treatment in multi-cultural societies. As the United States is a multi- cultural society, more resource materials need to be developed regarding cultural issues that impact on treatment. Courses in cross-cultural issues should be incorporated into medical education, as well as into the training of mental health professionals. Also, professionals need to be aware of the importance of using specially trained interpreters for reducing miscommunication and affecting compliance and treatment outcome.

Patient Education

Involving patients themselves in the communication process is of utmost importance, as research in the U. S. and abroad continues to show. Assertiveness training, coaching in question-asking techniques, and providing feedback on what transpires in medical consultations, lead to increases in patient satisfaction and compliance. Support should be given to projects that focus on the development of coaching techniques, such as video tapes and other materials, that help patients learn about their illnesses and disabilities and communicate their concerns to their physicians. Support groups and consumer advocacy groups can play an important role in this educational process, including the production of materials for patients, physicians, and mental health professionals.

In conclusion, this study confirmed the need for improved sensitivity and communication in patient-physician communication can have positive effects on:

❖ *Compliance*—those who participate more in their own care are more likely to follow physicians' directives; ❖ *Costs*—including psychological care as part of medical treatment results in fewer medical visits; ❖ *Quality of care*—patients will feel freer to communicate with their physicians, and physical and psychological needs will be more easily recognized; ❖ *Quality of life*—communication leads to satisfaction with care and an improved quality of life. Recent research suggests that for some conditions incorporating psychological interventions into medical treatment may even affect longevity.

❖ *Awareness of Behavioral Limitations After Traumatic Brain Injury: A Cross-cultural Study of New Zealand Maori and Non-Maori*

G. Prigatano, Ph.D., Barrow Neurological Institute, St. Joseph's Hospital and Medical Center and Massey University, New Zealand

A major question surrounding the field of neuropsychological rehabilitation after brain injury is whether or not the patient's altered awareness of their neuropsychological impairments is due to a psychological defense mechanism (i.e., denial) or is mediated by disturbances of brain function. It has been argued that in cultures that have a strong work ethic and which emphasizes productivity according to Western standards, that denial of disability of any type is more common.

In New Zealand, two traditions exist side by side which allow for the assessment of this question from a scientific point-of-view. The British New Zealanders carry with them many of the values ascribed to by Western countries including the United States. There is also the Maori population which does not seem to put as much emphasis on these traditional Western values and, as a group, appear to be more tolerant of deviation in behavior.

Through the support of Massey University and the International Exchange of Experts and Information in Rehabilitation (IEEIR) Prigatano studied altered awareness in Maori New Zealanders as well as in English ancestry New Zealanders. To his surprise, Maori New Zealanders with traumatic brain injury did not show the same degree of underestimating their behavioral problems compared to English ancestry New Zealanders with TBI. However, there was a confounding in the experimental design between the ethnicity of the subject and possible lesion location. This initial bit of research, however, has alerted us to more carefully assessing both cultural factors and the role both right and left hemisphere impairment and how patients perceive their disabilities.

❖ Special Education/Rehabilitation Education

❖ An Application of Australian Distance-Education Models to Rehabilitation Education in the U.S.

Chrisann Schiro-Geist, Ph.D., Director of Graduate Studies, Division of Rehabilitation Education Services, University of Illinois, Urbana-Champaign

Dr. Chrissann Schiro-Geist visited five Australian universities and had an extensive visit with a colleague in rehabilitation from a sixth Australian Institution in the states of Victoria, New South Whales, and Queensland, Australia in June and July of 1993. The purpose of Dr. Schiro-geist's visit was to review the history, curricula, and models of dissemination of distance education models of graduate education, especially emphasizing those distance models used by Australian rehabilitation educators to see if the models would be appropriate for replication in the U.S.

There has been an extensive history of distance education in Australia especially emphasized since the end of World War II when university educations became especially important for citizens of Australia. Distance education models for elementary and secondary education have been extremely longstanding within this country which has a fairly small population and a huge expanse of and. Models of distance education are primarily based on correspondence study but include a variety of important telecommunication advances including interactive television and radio, videotapes, public broadcasting, and the limited use of residential schools. All of these models would seem applicable to needs faced by U.S. rehabilitation and service trainers when students are from remote areas not easily serviced by traditional face-to-face training, or when needs of persons with disabilities who cannot travel or stay at traditional face-to-face settings need to be addressed.

Dr. Schiro-Geist will develop a report as a summary of her trip and will set forth the exact details of the Australian models and how they might be appropriately used in the U.S. graduate rehabilitation settings. She will also discuss the pros and cons of adapting such models, including issues of financing, faculty workload, and the social acceptance of nontraditional models.

❖ Special Education in Rural and Isolated Areas of Northern Thialand

James and Sheryl Tewksbury

James R. Tewksbury and Sheryl Tewksbury recently returned from Chiang Mai, Thailand where they conducted a pilot of the *Collaborative Liaison Project: Southeast Asia* (CLP) from December-March 1993. A demonstration project, the collaborative planning of a workshop on disability sponsored in part by a fellowship from IEEIR, became an integral component of the pilot. The Faculty of Education at Chiang Mai University under the leadership of Dean Prasit Malumpong and Associate Dean Annop Pongwat, hosted Mr. Tewksbury's study visit and are serving as a key Southeast Asia affiliate to the Collaborative Liaison Project.

Background

The ideas for this venture had been developed in 1989/90 when the Tewksburys travelled independently throughout Thailand where they purposefully visited several universities and colleges. During these visits, they explained that because of their professional backgrounds of many years of work in higher education and their current interest in international work they were very interested in learning about the work of their Thai colleagues. They communicated a desire to participate in a collaborative fashion. Since their travels were not sponsored by any agency or institution, they were free to respond to the interest and directives of a Thai host. After further discussion and exploration of possibilities, an invitation was extended from the Faculty of Education at Chiang Mai University where they mutually arrived at a title for their position as "visiting collegeaues" which described an understanding that their work would be collegial and voluntary.

The Western expert often neglected to equally value the Thai expertise and arrived at solutions which were not necessarily culturally sensitive or relevant. This type of model has typically set up the expectation and dependent behaviour associated with the idea that the "needs" of the developing nation will be resolved by the Western expert

The CMU faculty graciously arranged for site visits, attendance at graduate student presentations in rural villages, and for informal professional discussions. The Tewksburys learned about the many action projects taking place in northern Thailand via educational outreach programs sponsored by the Faculty of Education at Chiang Mai University. For example, they observed graduate students using hand made media to educate rural Thai villagers about alternatives to sending their young daughters and sons to Bangkok and Chiang Mai to work in factories or in prostitution. The Tewksburys were impressed with their

colleague's dedication to the mission of making education practical and of showing how knowledge could be put into action to address current social concerns.

The Tewksburys found that their independent informal status as visiting colleagues helped them to establish over time a collegial relationship of comfortability and trust which encouraged the open sharing of ideas, attitudes and feelings. Their colleagues explained that for many years, Thai educational institutions have worked with Western experts on various "aid" projects and most often the expert consultive model has been used. Typically, the Western expert personally received a substantial amount of funding which was especially disproportionate to the salary of their Thai counterparts. In addition, the Western expert often neglected to equally value the Thai expertise and arrived at solutions which were not necessarily culturally sensitive or relevant. This type of model has typically set up the expectation and dependent behaviour associated with the idea that the "needs" of the developing nation will be resolved by the Western expert.

From these discussions, James and Sheryl learned about the importance of valuing the perspective of the indigenous experts and of working collaboratively. Their inquiries as to what had and had not worked well lead to discussions of what type and style of cross-national efforts could be beneficial and responsive to Thailand and to the United States in the 1990s.

...by collaboratively sharing information and experiences cross-culturally, people can realize the potential of finding the most effective and beneficial approaches to their own work as well as to the work of their colleagues throughout the world.

It was during those months of conversation and work with their CMU colleagues that the Tewksburys began to collaboratively develop the concept of what would become the **Collaborative Liaison Project: Southeast Asia.** Three key topic areas of focus for the project were identified as: disability, women's issues, and environment. The project's overall purpose is to foster global perspective through cross-cultural communication and participation. It supports the idea that by collaboratively sharing information and experiences cross-culturally, people can realize the potential of finding the most effective and beneficial approaches to their own work as well as to the work of their colleagues throughout the world. The project's liaisons reside and work for six months in Southeast Asia and for six months in the United States. As liaisons, they share (broker) the work of their colleagues and promote collaborative cross-cultural projects and exchanges.

The project operates on the premise that we are Same, Same, But Different and that the full and direct understanding of commonalities, as well as the celebration of differences, promotes a positive world view about the human condition and offers the opportunity to participate globally in doing one's work.

Ideas are Piloted

James and Sheryl had the opportunity to put these ideas into action by returning to Chiang Mai University in December 1992 to finalize the project's formal affiliation with the Faculty of Education. Once again, they met with colleagues to learn of their latest activities and action projects. It was decided to elaborate the potential of the CLP through a demonstration project under the topic of disability. The IEEIR study visit fellowship supported a series of site visits to various educational and service programs for persons with disability. These site visits to residential schools and medical facilities were recommended by their Thai colleagues as representative of the current service delivery models in northern Thailand. Furthermore, they arrived at the idea of establishing a collaborative planning group for the purpose of designing and conducting a one day workshop entitled DISABILITY: A CONVERSATION ABOUT EDUCATION AND SERVICES. The focus of the planning was on the model of collaboration. Of particular importance was the desire of the planning group to bring together diverse voices and perspectives related to the topic of disability. The group invited persons with disabilities, parents, representatives from the Ministry of Education, local government officials involved with provisions and programs for persons with disabilities, University personnel, pre-professionals in human service fields, direct service providers, and advocates. There was initial concern about how to establish an environment where all voices would be spoken and heard. It was suggested that because of cultural tradition as well as professional hierarchical structures some participants would not speak in front of their elders or superiors. Through further exploration of this concern it was agreed that particular strategies could be employed to encourage equal participation and the valuing of all perspectives. The title of the workshop with its emphasis on a day of conversation is one example. Also, the introductory remarks were designed to speak to the valuing of grass roots efforts and to the idea of everyone figuratively leaving their degrees, titles, and professional "hats" outside the workshop doors. The one day workshop was held on March 12, 1993 at the University's Conference Center and was attended by 40 participants.

It was reported by many who attended the workshop, that it was the first time they had considered hearing and valuing what a person with disability or a parent thought about the topic of disability. One professor shared, "Even though I had studied special education in the U.S. and now teach an introductory course, I had never considered the importance of knowing how the parent of a disabled person felt." Another participant commented, " The experiences and ideas of many participants gave me a broader perspective about special education."

The Tewksburys observed and noted that some participants initiated networking by deciding to form a club. For example, throughout the day parents expressed a desire to link up with other parents and parent organizations. Some of the direct services personnel realized that they "saw" or worked with many of the same clients/ patients yet had never developed a team meeting approach to the delivery of services. They articulated how they were now seeing their work as interconnected. The

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Tewksburys contend that these examples suggest that both collaboration and the opportunity for equal voice hold great potential.

Thoughts And Impressions

The Tewksburys are actively examining the results of the workshop experience and the pilot project. A translation of the workshop proceedings as well as notes from an interpreter have been transcribed and offer rich material for analysis.

Slowly and effectively the poor and working Thais are increasingly participating in matters of social concern and are learning how to advocate for their rights. The time for innovative models of cross-national work has become even more essential to Thailand and to the United States.

As they reflect upon the pilot, it is apparent that the potential for success in cross-national efforts depends upon the open, honest and equal relationship of all involved. Though cultural particularities, customs, histories and established hierarchies exist, it is suggested that truly working together as collaborators is a foundation for future successes of cross-national efforts.

Future Plans

Meanwhile, the political and social scene in Thailand continues to change as it rapidly modernizes and establishes itself as a newly industrialized nation (NIC). The most recent democratic movement of May 1992, has led to the election of a civilian Prime Minister after many years of military control in the government. The ensuing months have been filled with examples of grass roots activities around such issues as forest encroachment, dam building, and child prostitution. Slowly and effectively, the poor and working class Thais are increasingly participating in matters of social concern and are learning how to advocate for their rights. The time for innovative models of cross-national work has become even more essential to Thailand and to the United States.

Therefore, the Tewksburys are pleased to announce that the School of Education at California State University, San Bernardino recently accepted an invitation to serve as the projet's key affiliate on the U.S. West Coast. The Foundation at CSUSB will provide services such as conducting funding searches, grant proposal writing and administrating grant awards for the CLP. The Tewksburys will serve as CSUSB and CMU faculty members and as field representatives in Thailand.

❖ *Effective Solutions in Rehabilitation: Learning from Each Other*

Charlene Butler, Ed.D.

Societies throughout the world are searching for ways to deal with some of the most difficult human challenges—food, housing, employment, health, education, transportation, the environment and disability. Solutions to these problems have tended to flow from developed to developing nations with the underlying premise that our knowledge, practices, equipment, and technical expertise was superior. But is this true? Have we nothing to learn in return?

In 1991-1992, Butler spent ten months traveling through Greece, Turkey, Egypt, Kenya, South Africa, Seychelles, India, Nepal, Thailand, Singapore and Indonesia. She was looking for innovative ideas in the medical, educational and social care of disabled children as an IEEIR fellow and under the auspices of Ashoka. Both organizations are committed to discovering and disseminating innovative ideas and in linking creative people together throughout the world for mutual solutions to our common problems.

What did she find? She found that there is a great resource of energetic, dedicated, well-educated, skilled and resourceful professionals concerned about disability in developing countries. She learned that ideology and technology cannot flow, unmodified, from developed to developing countries, and that outsiders' assessments of what needs to be done are often not correct. Developing countries are beginning to contribute their own culturally appropriate and practical solutions in designs, materials, techniques and programs that are based on established scientific principles and accepted concepts of normalization and integration. Butler saw superior work which she brought home to share with her colleagues for use here in the U.S.

CBR Workers - South Africa

One of the most outstanding examples of innovative work anywhere is COMMUNITY-BASED REHABILITATION WORKERS.

...she saw her task to be passing on basic rehabilitation skills to empower the community to take responsibility for their health and decrease their dependency on the too-few medical experts...Health care professionals will find it an excellent model for conveying information without medical jargon.

In South Africa, a physical therapist named Marian Loveday created a training program to meet the overwhelming need for health care in the area's black townships and squatter camps. The only P.T. for 300,000 people, she saw her task to be passing on basic rehabilitation skills to empower the community to take responsibility for their health and decrease their dependency on the too-few medical experts. Though this was designed to train rehabilitation workers with very minimal education in severely disadvantaged settings, the content has wide application. Teachers, paraprofessionals, volunteers, parents and family members

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everywhere could benefit from the cogent explanations.

Health care professionals will find it an excellent model for conveying information without medical jargon. The training program is an intensive four-week course taught in the language of the local area. The only prerequisite is to be able to read and write. The attractive manual contains the course content and suggestions for teaching, including how to incorporate traditional beliefs. Explanations of diagnoses and treatment are simple, yet capture fundamental concepts that enable understanding of complex ideas and lead naturally to "treatment". Attractive drawings help illustrate the concepts which are presented in the larger context that the rehabilitation task is to facilitate as normal development as possible in a loving, caring environment.

Early Intervention - India

A superior early childhood intervention program for parental use has been developed by an interdisciplinary group in India and tested in seven centers for children with developmental delays (birth to two years of age) under the direction of Dr. Nandini Mundkur. This program is relevant and understandable to parents because it focuses on self-help tasks sequenced in order of appearance in normal development. Each task has been analyzed for prerequisite skills from the motor, language, cognitive and social domains of development. The professional and parent identify the appropriate aspect of self-help or perhaps something the parent would like the child to be able to do, for example, feed herself with her fingers. The task analysis shows that five skills must be present: 1) motor skill (i.e., uses pincer grasp to pick up object), 2) cognitive skills (i.e., individually takes objects out of a container and performs simple gesture on request, e.g, clapping hands) and 3) language skills (i.e., points in response to simple questions and articulates using sounds to indicate preferred objects or needs). Activities and materials to develop the individual skills are described. UPANAYAN, A Program for the Developmental Training of Mentally Retarded Children (0-2 Years) is available in English in a written manual or as computer software (IBM compatible). It is being translated into a number of Indian languages.

Public Service Entreprenuer's - India

Butler's task for Ashoka was to identify potential candidates for their fellowships which support "public service entrepreneurs"—individuals who are producing tangible goods for the people with whom they work directly and are demonstrating models through which the problem-solving capability of society, in general, can be increased. Among the many competent and dedicated people she met, she was privileged to learn about eight who, indeed, stood out and were recommended to Ashoka. Dr. Bhaskaranand Kumar is one.

In southern India, Dr. Kumar is grappling with the need for technical aids, attempting to solve the problem on two fronts. He is concerned with the need for artificial limbs that are well-designed for comfort, function and appearance, but are also durable and affordable. The Jaipur foot, developed by one of Dr. Kumar's countrymen, has become the state-of-the-art standard artificial foot used in countries where most people go barefoot or wear sandals. Its design allows movement that is more functional than a prosthesis designed for a shoe and allows cheap and easy production using readily available materials in developing countries. Dr. Kumar is filled with ideas and projects, but developing an above-the-knee artificial leg with the same attributes as the Jaipur foot is his overriding focus of endeavor because the need is so great. About 1,000 people per year need artificial limbs in his own state. With his colleagues in a Prosthetics Lab at Kasturba Medical Hospital, he has developed such a leg (incorporating the Jaipur foot) and is ready to test its durability.

There is no lack of good ideas and creative people to solve the problems humanity faces. What is needed is identification of such people, encouragement and facilitation of their work, linkage and dissemination of ideas.

Though the cost is projected to be only about US$30, this is a princely sum for most people. Government funds which provided artificial limbs before 1987 are no longer available. Without insurance or government aid, few have the income to buy the artificial limbs they need. Hence, Dr. Kumar has also devised a creative funding plan. He has set up a fund to which people make donations. The unusual aspect of it is that donors will be allowed to withdraw their money if they should ever wish to do so. In the meantime, the interest that accrues will be used to subsidize the cost of the artificial limbs for those who need help.

There is no lack of good ideas and creative people to solve the problems humanity faces. What is needed is identification of such people, encouragement and facilitation of their work, linkage and dissemination of ideas. Moreover, Butler discovered that she began to look at her own work here with a fresh perspective and question much of what she simply accepted before.

❖ *Cultural Perspectives in Development of Rehabilitation-Related Education: The U.S. and Malaysia*

Jocelyn Armstrong, Ph.D., Associate Professor, Division of Rehabilitation Services University of Illinois at Urbana-Champaign

A study-visit conducted during June and July, 1992, was designed to enhance the knowledge base in rehabilitation education through information on the social and cultural aspects of disability and rehabilitation from the Southeast Asian country of Malaysia. Interviews, observations and literature searches were completed to collect baseline knowledge on a set of six interrelated topics: definitions and explanations of disability; attitudes and behaviors concerning rehabilitation; social supports for living with a disability; social integration of persons with disabilities; social policy for formal rehabilitation programs; and the nature and scope of existing programs. Armstrong's report presents a summary of the knowledge gained and suggests ways in which it can be used to both advance the incorporation of cultural perspectives and content into the curricula of rehabilitation education programs in U.S. and support the development of rehabilitation-related education and training in Malaysia.

The project sought baseline social and cultural knowledge of disability and rehabilitation in Malaysia with a focus on concepts of disability, their social consequences, and the ramifications for habilitation *and* rehabilitation. The purpose of the project was to enhance the knowledge base for rehabilitation-related education in the U.S. especially with respect to cultural perspectives, and to advance the resources for rehabilitation-related education and training in Malaysia. Data collection was by means of interviewing, observation and literature searches. This summary report covers work completed during the period from arrival in Malaysia on 28 May through 30 June 1992.

The project's main method of data collection was interviewing. Semi-structured or informal interviews have thus far been completed with persons with a diversity of physical and sensory disabilities, rehabilitation-related professionals, practitioners, persons involved in disability related training programs, voluntary organization personnel, and volunteers in disability/rehabilitation settings. Additional interviews were conducted with representatives of the community at large who are nondisabled.

Observation was used to gather information on the environmental settings of disability and rehabilitation and to provide context for the interview material. Most interview sessions were in settings which provided useful observation opportunities. Additional opportunities or planned observation have included workplaces, sporting events, voluntary organization activities (including the biennial meeting of a national disability self-help organization) and several service delivery sites and other opportunities are planned.

Literature searches in support of this project were begun during visits to Malaysia in 1990 and 1991 and they are continuing at research and university libraries and through invitation to consulting agency and organization resources. The planned sampling of local mass media presentations of disability issues proceeds will be by way of regular review of English-language newspapers and magazines.

❖ *Technology and the Implications for Inclusion of Special Education Students: Perspectives From Japan*

Betty Rankin and Ann Haring, Public School Teachers, Loudoun County, Virginia

Recent press comparisons between education in Japan and that in the United States have called the attention of educators to the cultural differences and similarities of the two societies. Often such reports minimize the differences between the two educational systems. The understanding of any system is dependent on the cultural interpretations and perspectives of the observers.

The cultural difference between the United States and Japan are considerable and a common educational terminology is lacking. Although the same words may be used by each, the cultural differences do not allow for the same meaning. Diversity in the classroom is a good example. To educators in the US diversity means students with various racial, ethnic, family backgrounds and different learning styles and abilities. To Japanese educators, it means regional, social or occupational differences within families. Students with disabilities are a separate category with which the majority of educators in Japan have no contact.

The 1992 IEEIR Fellowship provided the means for a birds-eye view of Japanese education and allowed for some insight and exchange of information with a select group of educators. Lack of time and common terminology hindered gaining a more in-depth understanding about attitudes towards people with disabilities. However, the first hand exchange with Japanese educators and a homestay experience provided immeasurable knowledge. Both U.S. and Japanese educators expressed a desire to look beyond their respective countries to a global community which encourages a full range of human interactions among all students and adults. Many Japanese educators expressed concerns similar to those of some U.S. educators regarding students with disabilities. Until all educators embrace the concept that equal access to educational opportunities is a student's right, regardless of ability, inclusion will continue to be illusive.

❖ Community-based Rehabilitation Programs and Concepts

❖ Improving the Effectiveness of Consumer Participation: Community Based Rehabilitation Schemes as a Model for Consumer Responsive Disability Support Systems

Alexandra Enders, Associate Director Rural Institute on Disabilities, University of Montana

Alexandra Enders' IEEIR fellowship study in South India (March-April 1993) was planned to evaluate assumptions of US rehabilitation and independent living (IL) approaches within the context of community based rehabilitation (CBR) scheme(s); to identify aspects of grassroots CBR strategies that can be integrated effectively into a consumer-driven, community-based model for rehabilitation and disability support services in the U.S.; to identify analogies useful for inclusion in U.S. health and disability policy decision-making.

Enders gained a new appreciation for the U.S. Vocational Rehabilitation (VR) system, and realized that if it didn't exist we would have to invent one. Recognition and active incorporation of economic development/ community development strategies into the State-Federal VR partnership might allow grassroots VR counselors to better facilitate and implement the intent of ADA in their communities.

Enders' purpose was to challenge the assumptions of her beliefs by looking at disability through a different baseline set of practices. She did not intend to export information from any particular program or model, but expected to gain new insight into how CBR and related natural support systems might conceptually and programmatically be incorporated systematically into Independent Living Centers in the U.S. In fact she discovered much more. The trip was full of "aha" insights, some fundamental, many quite surprising. A few of these include:

Integration of VR and Economic Development

Interest in economic development models led Enders' to Indian hosts who had actively incorporated traditional development work with rehabilitation efforts. The orientation in development work on changing the environment, in particular the economic environment, in order to provide access to increased local options, seems exactly in step with the Americans with Disabilities Act (ADA). She gained a new appreciation for the U.S. Vocational Rehabilitation (VR) system, and realized that if it didn't exist it would have to be invented. Recognition and active incorporation of economic development/community development strategies into the State-Federal VR partnership might allow grassroots VR counselors to better facilitate and implement the intent of ADA in their communities. An ecological approach could be fostered that moves beyond sole focus on the individual's adjustment to disability; and incorporates targeted efforts at developing the community's ability to include all its members. International development work clearly shows that access is not just physical, but is rooted in the community's economic viability. Disability as a poverty issue is more easily recognized in a developing country, but is equally true in the U.S. However, as Dr. Maya Thomas, the ActionAid-India host stressed, rehabilitation efforts cannot be just incorporated into development work; they must go hand in hand. If the individual's body needs "fixing" (e.g., surgery), or function needs "fixing" (e.g., therapy and/or training), you cannot just "fix" the community and expect people with disabilities to automatically achieve equity with their neighbors.

In rural America, VR counsellors in order to be effective in placing individual clients, often need to do community development work. They just don't tell anyone, and even feel they might be penalized if the "system" knew. Rural areas in the U.S. could provide a good venue to test models for integrating VR and economic development strategies, perhaps through the choice demonstrations included in Title VIII of the 1992 Rehab Act Amendments. As part of any model "waiver" program it would be necessary to develop indicators (and status codes) which accurately reflect community as well as individual impact. We could learn by collaborating with international colleagues, since traditional development indicators do not work well as disability related indicators. An additional benefit to consistent integration of vocational rehabilitation and economic development is the transfer of rehab strategies into regular development efforts. Building inclusive community support systems may sometimes get its foundation in disability services. For example, in the U.S., a disability oriented employment program (Pathfinders) in Indiana, developed a job bank for its clients. The community also needed a job bank. Instead of developing a separate one, the Pathfinders job bank has been developed into *the community job bank* for everyone in a multi-county area.

Other fellows' CBR summaries appear elsewhere in this publication, e.g. Pauline Ginsberg, James and Cheryl Tewsksbury, Barbara Sher and Charlene Butler

Recognizing Elephants

The working title for Enders' fellowship report is *Recognizing Elephants*, referring to the fable of the three blind men and how they describe the elephant in their midst. It became clear to Enders visiting village programs, and rereading CBR literature, that the field (locally and internationally) shares little consensus on what CBR is, or even what rehabilitation, village, rural, or community mean! Yet we talk as if we indeed have commonly

Continued on next page

agreed upon definitions, assumptions, and frameworks. Indicators, evaluation strategies, replication predictors, training methodology and content need to be built from consensus understanding, and need to be framed to clearly identify the perspective, assumptions, and bias of the developer(s).

There may be as many definitions of CBR as there are people practicing it! We need to work together to develop a clear way of talking about our differences; which may not be popular, but would clear up a lot of confusion and professional bickering. CBR has become trendy, and is too late to tell others to stop using the jargon just because you may not think what they are doing is *real* CBR. We must be able to accurately describe which part of the universe of CBR is being addressed if we are to develop appropriate evaluation tools, indicators of success, training materials, etc., which have any chance of being transferrable. CBR is an elephant, and although there may be subtle differences between Indian elephants and African elephants, neither can be understood by describing the feel of a trunk, a tusk or a tail.

Rural areas in the U.S. could provide a good venue to test models for integrating VR and economic development strategies, perhaps through the choice demonstrations included in Title VIII of the 1992 Rehab Act Amendments.

The missing 8%

Another lesson was drawn from a combination of concepts from development and prevention, ambiguity about definitions and the number of people with disabilities. In disability statistics, there is frequent discussion about the discrepancy between the 10% of the population W.H.O. claims to have disabilities, and the one to two percent found in most surveys in developing countries. Since there are numbers as high as 23% in the U.S., one to two percent seems low; especially when it is estimated that 75% of the people with disabilities in the world live in developing countries. The professional debate seems rather academic. The relevant issue seems to be what is going on in the missing 8-9%. The issues are imbedded in community perception, as Mike Miles, Dr. Prabhu, and others have noted. If your community and your family doesn't see you as disabled, are you? Dr. Pruthvish, program advisor to ActionAid-India, Disability Division, believes that we need a concept like *wellness* in the disability field. In the health promotion field, we are learning to ask not only "what makes some people sick?" but also "why are people healthy?" In the disability field, we should also be asking "why are some people with disabilities not (seen as) disabled?" and "what kind of communities/support services can facilitate reducing the 1-2% to 0%?" (Note, the disability isn't gone, just the segregating label.)

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Development often focuses on the empowerment of marginalized people. People with disabilities frequently fit that category. But they may need a combination of regular development/ community organizing skills in combination with disability specific interventions. By focusing primarily on the physical and functional rehabilitation aspects, the importance of empowerment and community integration can get lost. As people are identified (labeled) as being disabled and needing special rehabilitation services, including CBR type interventions, they may also be set apart from their communities, become more isolated, and hence less empowered. There are serious questions to be addressed in doing survey work to identify (label) people as disabled, especially when no interventions are available. The principle of "Do no harm" should apply. How necessary is the survey data for planning? At what point do the risks of labeling become less than the intervention introduced? Learning more about what is working with the missing 8% could provide answers. These studies may only be possible in developing countries, because of the widespread labeling in more developed countries. Even in Sweden, you need a diagnostic label to get disability-related benefits. It would be of enormous benefit internationally to develop models where people could get the support services they need, without having to own a stigmatizing label. Looking to development efforts may provide clues; learning more about the 8% may provide direction at home and abroad.

❖ *Providing Occupational Therapy to Low Income Populations in Rural and Urban Settings* *Barbara Sher MA, OTR, Whitethorn, CA*

During the months of January through March, 1993, Barbara Sher had the opportunity to travel to **Hong Kong and New Zealand** to see how occupational therapists serviced the low income population in an urban (H.K.) and rural (N.Z) setting.

As part of her research for the World Rehabilitation Fund on what is going on for occupational therapists in New Zealand, she found that in the North Island there is a fairly standard set of programs that serve the pediatric population. Rita Mendes, OT from Wellington described the following programs:

1) *Early Intervention Centers (E.I. Centers)* are funded by Crippled Childrens Society (CCS) which is a private charity. E. I. Centers provide direct therapy in groups and one to one, parent support groups, preschool groups, toy lending library, parent relief program, training programs for teacher aids and volunteers and provide lobbyists to support public access. Children are referred to this program through pediatricians, Plunket Nurses (Public Health Nurses who run well baby clinics) and parents. CCS gets its funding through annual fund-raisers mailings, events such as Fun Runs which includes disabled and wheelchair participants. They are also supported by the Australian and New Zealand Bank (ANZ) which encourages people who give more than $10 to CCS by entering their name in a drawing. Parents also pay a token amount for services.

2) *Visiting neurodevelopmental therapists* are government funded. These visiting therapists can be either PT or OT. Their role is to assess and treat developmental problems in young children in the areas of physical function, learning language and self-help skills. They provide a detailed assessment and update a home management program, advise on any necessary housing alterations, loan therapy equipment and liaison with other services. Their main function, as they see it, is to give primary caregivers support and education. They see children once a week, once a fortnight or once a month. Children are also eligible to receive toys and tapes through the National Correspondence School for Special Needs Children in which they can have toys and tapes mailed to them and then return them without any postage charge. The school is based in Wellington which is in about the center of the country.

3) *Parent Action for Conductive Education (PACE)* is a group of parents who pay for Conductors to come here from Budapest where Conductive Education got its start. They are presently employed in four schools in Wellington and children with disabilities go to these schools from 10 am to 2 pm and their parents go along so they can learn the techniques and apply them in the home situation since conductive education is a 24-hour-a-day program.

4) *Early Intervention Trust (EIT)* is an organization that is similar to Early Intervention Centers but was started originally by parents of children with Down Syndrome and now includes parents of children with other disabilities. The direct therapy is mainly one to one intervention and the parents pay for services. This organization is better known for being the first one to contact parents in the hospital right after the birth to give emotional support.

Other Programs

Another interesting program in the North Island is directed by Janice Conroy and is called Whakaawhi which is the Maori world for "safe options." It is a program designed to assist young mothers and mothers-to-be from the ages of 13-20 who need support. Their aim is to give people knowledge and skills to enable them to live in the community as a viable, healthy and independent family unit.

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...A. Enders

Their service includes choice of either live-in residential care or day care support. The residential care is a home with 9 beds in which a woman can stay up to 9 months, and an education and counseling program.

The education program emphasis is on self-esteem, development and self-management subjects such as diet and nutrition. Other topics are preparation for parenthood, baby care, budgeting skills and planning their own further education. Counseling is for families and for physical, sexual, mental and emotional stress and to discuss the options of adoption or foster care. Their prenatal care is provided by General Practitioners or Domiciliary Midwives. Often, long term relationships are formed between the women and their midwives. Funding from a private source has recently been approved to start a Mobile Service to serve indigenous people in rural areas. An occupational therapist is on the advisory committee.

Another unrelated but interesting fact about life for children with learning disabilities in New Zealand is a group called SPELD, Special Education for the Learning Disabled and is composed of mainly retired teachers who do one to one tutoring of children in their homes. There are assessments made of the children and a program written by educational psychologists or other trained individuals and then these programs are carried out individually. Children who need specialized motoric programs are referred by the SPELD teachers to OTs or PTs.

❖ Advocacy

❖ Parent Advocacy and Family-Centered Care for Children with Disabilities and Their Families—Linking North American Experiences with Eastern European Initiatives

Polly Arango, Algodones Associates, Inc., Algodones, NM; William Carl Cooley, MD, Associate Director for Clinical Services, Dartmouth Center for Genetics and Child Development

As the largest city in Slovakia (pop. about 500,000) Bratislava is the cultural and scientific center of the country. The site visit in Bratislava was highlighted by a meeting attended by thirty parents of children with disabilities who have been served by a community-based outreach center for infants and toddlers supported by a local tertiary care medical center. Other visits were made to a model inclusive preschool program, two multi-disciplinary evaluation centers with intervention and education programs, and a four-year high school level vocational training program for careers in preschool education and early child care.

One afternoon included a four-hour conference during which the visitor from the United States joined an agenda of presenters from the Bratislava area on New Systems of Service and Care for Children with Disabilities and their Families.

Prague is the capital of the Czech Republic and remains a city of great natural and architectural beauty. The city is divided into a number of municipalities, each with its own political structure for education and other public concerns. The Prague site visit was focused on activity in a section known as Prague 2 from which the community leaders had attended the June 1993 conference in Washington. Dr. Cooley and Ms. Arango were featured presenters at the monthly meeting of ACCORD which is a parent support organization involving families of children with disabilities who live in Prague 2. The group has recently received a grant from the Ministry of Health that will provide funding for office space and a part - time coordinator/director. A second grant to develop two model sites for inclusive education—one in a preschool and the other in a primary (elementary) school—has also been awarded to ACCORD. Community visits during the stay included the sites for the inclusive education project and a one-year-old group home in suburban Prague which is locally regarded as a state of the art facility for persons with disabilities of all ages. Early plans were discussed with the head of the child neurology clinic at the main tertiary care medical center in Prague for the development of multidisciplinary teams to serve and support families with children experiencing complex disabilities requiring multiple health-related services. Families in Prague and Bratislava were found to share the same kind of concerns as families in the United States. They regard themselves as the best advocates for their children and value supportive relationships in which they are respected and heard. Their countries are generally more supportive of families with children than is the United States (both Slovakia and the Czech Republic provide three years of paid child care leave for mothers of young children). However, parents regard their societies as less tolerant of people with differences and less ready for full community inclusion. This perspective creates a tension between what parents wish for their children and what they feel is currently possible. Many parents seem ready to devote energy to systems change in their communities, but often need training and support in their new roles as community activists. Parents were very enthusiastic about a system of direct parent-to-parent connections arranged during this visit with parents in the United States. A system for translation of letters to and from English was developed in both Prague and Bratislava.

This study provided an opportunity for Dr. Cooley and Ms. Arango to relate all of the stages of their professional and parental experience to another country's values, needs and goals. Family-centered care is a universally applicable "best practice." This project tested that hypothesis.

❖ Development and Disability: Voices from the Periphery - Zimbabwe

James I. Charlton, Executive Vice President, Access Living, Chicago, Illinois

For the last eleven years Charlton has been deeply involved in the disability rights movement both locally and nationally. He has been most interested in issues as they relate to the continued segregation of the disabled community and how and why disability related organizations have emerged to confront discrimination.

Having travelled throughout Central and South America and, through an IEEIR fellowship, to Zimbabwe, Charlton has been able to have discussions with many disabled activists on how they perceive barriers.

Charlton's fellowship report has been included in IEEIR monograph #53 *Traditional and Changing Views of Disability in Developing Societies: Causes, Consequences, Cautions.* Charlton briefly describes and analyzes the major contradictions the disability rights movement in Zimbabwe confront within the context of underdevelopment and dependency. That is, how the ironies and complexities of the economic, cultural and political milieu of Zimbabwe today influence the lives of people with disabilities and their movement for equality and rights.

The approach is to use edited interviews of four leading disability rights activists in Zimbabwe to help describe through narratives their experiences and analysis. These interviews were conducted through an IEEIR fellowship in March of 1992.

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❖ Sensory Disabilities

❖ West Eyes East as Diabetes Spins a Web

Margaret E. Cleary, Carroll Center for the Blind

The significantly increased incidence of diabetes mellitus (DM) and visual impairment in Japan stimulates improved sharing of concepts and techniques among rehabilitation personnel. Independence and self-esteem improve as facts are shared by people in both Japan and the United States. The perceived contribution of this study is recognition of factors which influence people of recent Japanese ancestry when encouraged to adopt DM self-management skills in the United States.

The evidence is clear that the incidence of DM increases in all people as affluence develops: less exercise, diet rich in meat and fatty foods, luxurious living, and stress. Americans can learn prevention techniques as they look at the positive aspects of such phenomenon as the basic Japanese diet, hygiene practices, interdependence among family members, and strengths of group consciousness.

There are frequently reported and confirmed factors which influence DM self-management for people who are visually impaired in Japan: ❖ The incidence of DM increases as affluence develops- less exercise, diet rich in meat and fats, luxurious living, and stress. ❖ The development of DM self-management skills has been given minimal attention due to the low incidence of the disease, absence of research data, and historical isolation. ❖ DM medical care and education programs are provided predominantly by the physicians. ❖ The strong social security system makes basic medical and rehabilitation insurance available to most people. ❖ Most adaptive aids, technical devices and instructional materials are available only through Western manufacturers. ❖ The Japanese homogenous national culture emphasizes rigid conformity, valuing group participation as well as minimizing individual differences and needs. ❖ Strict politeness rules affect the client/therapist relationship. ❖ Interdependence among family members flourishes. ❖ Pride in diet which evolves around rice, fish, soybean products, vegetables, natural mineral supplements, and fruits, disguises the impact of excessive sodium and other harmful dietary practices. ❖ Alcohol abuse has been identified as a leading problem. ❖ Exercise is desirable, but the strict work ethic allows little time for it. ❖ Meditation is usually incorporated into routine life-style. ❖ Medicines such as insulin and oral agents are used suspiciously. ❖ Self-monitoring of blood pressure or blood glucose occurs seldom, if at all. ❖ Fear of further complications is minimized by the statistical lower incidence of problems. ❖ Scrupulous hygiene practices exist.

In assessing the status of rehabilitation in regard to Diabetes Mellitus and Visual Impairment in Japan, it appears that Japanese treatment modalities, equipment, research, and practice are beginning to emerge. West learns much when eying East as DM proliferates like an ambitious spider. Rehabilitation workers benefit when considering the impact of basic Japanese culture on DM as well as a person's response to the disease. The evidence is clear that the incidence of DM increases in all people as affluence develops: less exercise, diet rich in meat and fatty foods, luxurious living, and stress. Americans can learn prevention techniques as they look at the positive aspects of such phenomenon as the basic Japanese diet, hygiene practices, interdependence among family members, and strengths of group consciousness.

Practitioners achieve greater success when learning as much as possible about their clients who have migrated. Preparation suggestions to enhance instruction of self-management skills to people of recent Japanese ancestry include: utilizing the input of family members; reviewing available manufacturers' instruction in Japanese; procuring translators; learning common phrases in Japanese; contacting members of the local Japanese community for assistance; being active in international groups in professional organizations; attending appropriate conference sessions; and contacting medical research centers to consult with visiting fellows or resident physicians.

Many opportunities to share this information have evolved since the visit, including speaking sessions at several regional and national conferences, as well as a publication in the Journal of Visual Impairment and Blindness selected for print October 1993. Many Japanese visitors have been guests at the Carroll Center for the Blind this past year. Cleary is currently arranging for a young diabetes educator to spend a month in the United States studying and preparing for the United States Diabetes Educator's Certification Examination.

Exciting prospects have evolved from this brief study visit. Japanese people are eager to learn, to borrow, to copy, and to benefit from available expertise. Americans have opportunities to educate, to share, to learn, and to grow.

❖ *Sensory Change and Aging: The Australian Response to Age-Related Hearing and Vision Losses*

Martha Bagley, M.S., Specialist to Older Adults, Helen Keller National Center for Youths and Adults Who are Deaf-Blind

Ms. Bagley's fellowship was carried out during September and October 1991. Her host was the Association for the Blind, National Centre for Aging and Sensory Loss in Melbourne, Victoria.

The purpose of this study-visit was to identify programs, strategies and techniques that could be used to strengthen service programs for older Americans with hearing and vision losses. The most valuable product of the study-visit was the fresh perspective gained on how to best meet the needs of older adults with dual sensory losses. It is often necessary to leave the forest in order to more clearly "see" the trees.

In America, as in Australia, there are service agencies and self-help or consumer organizations for people with blindness, people who are old, and still others for people who are hearing impaired. Sometimes these organizations work together, but often they do not. Despite cooperative agreements or joint projects they tend to focus on their special "problem."

What rehabilitation service providers must do, regardless of the focus of their programs, is provide services that address the individual's unique need, based upon their dual sensory loss and age. Too often vision and hearing services are stuck together like two blocks of wood. The individual gains little benefit from these services because they do not consider the interrelated nature of sight and hearing or the chronological/developmental needs.

People who are sighted/hearing understand what goes on around them by both seeing and hearing it. We know that it is raining rather than sleeting, hailing, or snowing, not by just hearing it on the roof, but by also seeing it. When there is an impairment of one sense, hearing or vision, a part of the individual's understanding of the world is lost. Impairment of two senses creates an even greater barrier between the individual and the world.

Service delivery agencies and consumer organizations must realize that their clients and members who are blind, hearing impaired, or old are likely to be experiencing multiple problems that will affect the adaptive strategies and coping techniques that they are teaching. They must take the lead in recognizing dual sensory losses and in adapting their approaches.

Specifically, rehabilitation and aging agencies and organizations must: learn to recognize dual sensory losses and their effects on the individual; understand how hearing and sight are interrelated and the effects of impairment in one area on the ability to cope with impairment in another and promote that understanding among professionals and consumers; be able to adjust coping strategies that are heavily dependent upon one sense (hearing or vision); assist the individual in maximizing remaining vision and hearing, as well as developing alternate techniques, such as tactile communication, by providing complete information, and opportunities to experiment with and learn to use devices and adaptive techniques; and build bridges to other programs through cooperative agreements and working relationships that will allow the pooling of expertise, as well as cross referral.

A direct outgrowth of the IEEIR Fellowship study-visit has been the development of a model *Confident Living Program*, funded by the U.S. Administration on Aging. This program is designed to provide a structured learning experience, peer support and connection to community service providers to older adults who have hearing and/or vision losses.

❖ *Aural Rehabilitation: Materials, Procedures, and Implications: Learning from Australia*

Mark Ross, Ph.D. Professor Emeritus, University of Connecticut

In the U.S. alone, there are approximately 20 million adults with a hearing loss of sufficient degree to interfere or disrupt the communicative process. The major therapy offered to such individuals is a hearing aid. Clinical audiologists know that in many, perhaps most, cases while a hearing aid is a necessary precondition of aural rehabilitation (A/R) therapy, it is, in itself, insufficient.

It is only in recent years that the profession of Audiology has emphasized more and more the necessity of an organized therapeutic program that focuses on communication processes and communication coping strategies. In Australia, on the other hand, where Ross' study was conducted, such therapy has long been seen as a routine necessity for persons with hearing loss. In part, this is no doubt due to accountability considerations (many segments of the Australian population receive hearing aids free of charge). In response, the professional community in Australia has developed a number of A/R procedures, some variations of recognized A/R themes.

In the Ross' IEEIR study visit, the A/R procedures utilized in centers in Melbourne and Sydney were observed and discussed with the professionals who developed or refined them. The written report of the visit describes the different procedures and programs in detail. In one such program, for example, the exercises range from those relating to traditional visual and auditory cues to environmental tactics, anticipatory, conversational, adaptive and maladaptive strategies and one-on-one conversational therapy procedures. All procedures involve a number of examples, lessons, and "homework" assignments. Another program requires the client to ask the professional a graded list of questions on selected topics: the answers by the professional are designed to teach such skills as communication, repair strategies,

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and audio-visual reception, etc. A number of other procedures/ programs are described in the Ross' report, ranging from in-service training programs for the health care professional, a home-based audio cassette auditory training program, to a modified "tracking" procedure (where the client repeats the verbal stimuli and the errors are used for instructional purposes.

Since returning from Australia, the report has been disseminated to a large number of key Audiological professionals in the US. Versions of the report have been distributed in several national forums, and scheduled to be published in the *Journal of the International Federation of the Hard of Hearing and the Hearing Rehabilitation Quarterly*. Perhaps, however, the major future impact of the study-visit is the impetus it has provided to redefine A/R in this country: A/R must be seen in the same relationship to a hearing handicap as physical therapy or speech-language therapy is to physical or linguistic handicaps .

❖ *The Impact of Cultural Identification on Rehabilitation Services Among Aboriginal People in Australia Who Are Deaf, An Interim Report*

Nancy Eldredge, Ph.D., Assistant Professor and Director, Rehabilitation Counseling, Deafness Program, University of Arizona

I am writing this report from Doomadgee, Queensland, Australia. It is a remote community of Aboriginal people, and one of the reserves where Aboriginal people were put after colonization. The missionaries took three different tribes who were not natural allies and put them together in one mission (now a reserve), which was the start of considerable tension which continues today.

Here in Doomadgee, there is a school which on a good day has 250 students registered, though not all of them attend, and only a handful of whom are Anglo. All of the teachers are Anglo, although some of the parents from the "village" come in to work as classroom aides. The village is actually the row of government built houses on one side of Doomadgee proper; most of the Anglo residents live on the other side of town that seems to be separated by the hospital. I have been told that the separation of Aboriginal and Anglo people is the result of a decision made by the Council, as opposed to a policy initiated by the Anglo residents. The Anglo individuals are mostly hospital staff who are nurses and one doctor, the store manager and employees, the police, and "town" workers employed by the council. I am here working through and with the Aboriginal health team, Ann O'Keefe and Valerie Douglas, who have completed training in primary and preventative health care. These women have taken me through the village and introduced me to people, often their kin, and helped guide and lead the talks we have had ranging over topics such as "the old days" in Old Doomadgee Mission; ear problems; health concerns; traditional healing methods and bush medicine; causes of deafness; ideas about disability; hearing aids; race relations; American Indian culture; my family; skin color; the Sonora Desert; best recipes and methods for cooking goanna, kangaroo, wallaby, wild pig, and porcupine; the danger and variety of snakes; the problems of alcohol and the threat to the culture and morals it causes; and other topics too numerous to describe.

Political and Social Influences

Coming to Australia and doing a research project involving Aboriginal people is particularly affected by the larger political climate in the country. Recently a landmark decision was handed down in the courts that is known as the "Mabo Decision" which basically grants land rights to Aboriginal people who had traditionally been living on the land in olden times before colonization and the forced movement to reserves and/or stations. As a result of this highly controversial and debated land rights case, Aboriginal people are now filing land claims all over Australia, which has the non-Aboriginal population frightened that their land will be taken away and given to the Aborigines. From the Aboriginal perspective, the land that they want is Crown land or land that is leased land, not the land that currently has an owner sitting on it. But many Anglo Australians seem concerned that their backyards are in danger and that Aboriginal people will be filing claims for all of Australia. This controversy has sparked a resurgence of anti-Aboriginal feeling, and there are numerous cases of Aboriginal people who have been assaulted, and killed, by irate mobs of men.

A taxi driver in Perth on the way in from the airport told me that Aboriginals [sic] just want to take their dole [welfare] checks and turn it into drink; "they don't want to do anything but take their checks from the government. They pour dollars and dollars into them and it doesn't do any good. They don't pay any income tax. They don't want to work. It wouldn't be so bad if they'd do a bit of work, even pushing a shovel, but they just want to live on their weekly check. It all goes to alcohol. Ah, the full-bloods are ok; they stay with their own people, they're all right. It's just the mixed bloods that cause the problems. When they come down here and mix with the whites...that causes the trouble. They should stay up with their own people." When I asked him how they were supposed to get a job if they didn't come down to the cities, he said, "Well, that's a point I suppose."

Then in Townsville, I was sitting on the bench, waiting for the taxi to take me to the airport and an older fellow came up to chat (I'm being polite...when he found out I was American, he mentioned that he had done some mechanic type of work at one of the American Army bases, and when the weekend leave time came around, "they all rented some hotel rooms in the most expensive hotel around, and brought in some sheilas just for the night," looking at me hopefully.) At any rate, he just "went off" talking about the Mabo decision, echoing some of the sentiments mentioned above, and then saying, "You know we're not supposed to call them 'Abos' anymore. They just came out with some new decision, and now we have to say 'Abori-gi-nal In-di-vid-uals' now...ah, it's so sick!"

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So the political and economic climate is definitely having an effect on the life of the Aboriginal people here, if not on me personally as well. Before leaving for Australia, I had made arrangements with Polly Ballantyne and Ian Henderson of the Australian Hearing Services for people to contact regarding the research project sponsored by IEEIR. As a result of the contacts Ian had made for me, there were a number of people who had expressed doubts that I would be able to accomplish the project, partly because I was white, but mostly because the local Aboriginal Lands Councils, and in fact the national council overseeing Aboriginal health and other affairs would have to approve my visit, and the process would take at least 6 months, if I heard from them again at all. Part of the problem was that they were becoming more protective and sceptical (rightly so) about researchers coming in and then leaving, never to be heard of again. The same person who had sounded the most discouraging about me coming into the Aboriginal communities, also gave me the good suggestion about contacting health workers to get access to the rural locations.

The last three weeks before I left were frantic, with me faxing documents, explanations about the project mostly, calling people trying to follow up on the permission to come into the remote areas and talk with Aboriginal people. Andrew Remenyi and Jan Branson of La Trobe University were very helpful in trying to find out what was actually needed. It finally looked like I only needed the local authorities to give permission, so I then began my fax campaign to Travern Lea, the contact person for the Northern Regional Aboriginal Health Authority in Queensland and he helped me to get in touch with Helen Ruhle, his director, who would make the decision. Travern also contacted the Doomadgee Aboriginal Health team to see if they would be willing to have me, and local permission was granted by the Doomadgee Council. I got the final word that I would be able to come into this community, or others as I wished, on the Tuesday before leaving on the following Friday.

Cultural Influences

I received a number of cautions from people before leaving the States. I was told by more than one individual that it would take me several weeks just to establish myself in the community. One person told me that her way of introducing herself in the community was to "wear older clothes and go and hang about. It used to take me 6 weeks, but now I've gotten it down to about 2 weeks, and then people will begin to get curious about me and come up and ask what I am doing." Other people told me that I should be careful with my eye contact, because Aboriginal people don't make direct eye contact, and I could be considered rude. Another told me that I would not be able to ask direct questions, and only after an extensive period would people feel comfortable with me enough to respond to personal talk. Also, when talking with people in the city, usually Anglo people, whenever someone would mention happenings of a spiritual nature, or something involving a curse, they would lower their voices and look around saying, "Oh, we're not supposed to talk about this." And even here in Doomadgee, when I was talking some of the Anglo residents, when I mentioned going into the village to talk with people and visiting with them in their houses or on their front porches, several chorused, "Oh no, you can't go into their yards, you have to stop at the gate, they won't let you into their yards."

For whatever reason, my experience has borne out almost none of this. I think the main reason is that I have gone everywhere with the women who are the Aboriginal health team. We drive around in their car, people have seen me with them, and they have introduced me to their family and friends, and made me be accepted more readily in the community. The team members have also served to help interpret hard parts in the conversation, whether because of accents or slang, they have made the communication work. And one of the more interesting and unpredictable developments of the trip has been the response to me as a person whose great-great grandmother was Huron Indian.

Here in Australia, the history of Aboriginal people is such that in the old days children who had white blood in them were frequently removed from the families and taken miles away to be taught in mission schools and often reared by white families. The terms "half-caste, or quarter-caste" were terms imposed by white people on Aborigines as a way of identifying those who should be removed from their communities. The policy had an intention, if it had been continued, of perpetuating the genocide of the Aboriginal people, genocide that was actually happening with massive slayings of the indigenous population. Today, the Aboriginal people are fighting the terminology and seem to have adopted the stance that if a person has only one drop of Aboriginal blood, then they are Aboriginal, though some others would argue that to call yourself Aboriginal you should have been raised tribally. Another person told me that it is also the treatment by (white) society that makes someone Aboriginal.

The only incidence of profound sensori-neural hearing loss with an early onset I have found here in Doomadgee is in a 10 year old boy. His parents are obviously proud of him, and his father took pains to tell me what the boy is able to do that is similar to other children, for example, fishing because he watches carefully what to do, and turning somersaults like the others

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At any rate, when I have told people about my ancestors, their response has been to generally accept that I am Huron, though they have been very gentle with me about it, in case I might be still so "undeveloped" about acknowledging the "truth" about my ancestry. This refers to the fact that many Aboriginal people (meaning those with a good mixture of white blood) frequently did not identify themselves as Aboriginal, and in fact are just now beginning to do so with any regularity. So the attitude of many of the Aboriginal people I have talked with has been "poor thing, one day, when she is more self evolved, she'll be able to accept this Indian blood and may even be proud of it." In fact, I am proud of my Indian heritage, I just don't know anything about it, and I have not felt comfortable in claiming it because of that and also the practice in America of having to be a certain percentage of Indian blood to belong to the particular tribe. People have noticed my skin color, and have shown the greatest empathy possible when I told them about growing up in the South in times of

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segregation and the kidding that I got from peers and adults about being a "nigger" and having to "ride in the back of the bus." They were shocked when I talked about toilets, water-fountains and restaurants were designated as "white" or "colored." They, too, were indignant when I told them of the woman in Texas who came up to me in a store to ask if "there wasn't something to put on that skin to lighten it up." They all huddled a little closer one afternoon, as about 8 of us sat together knee-to knee on the porch, and one old "Auntie" rubbed my leg and arm saying, "You're a pretty color, such nice skin. You're right to be proud of it." During this time, they asked me very personal questions about how that treatment "felt" to me, and their eye contact and touch was direct and personal. And the depth of their empathy actually made me connect back with myself at 4 or 5 years of age, realizing in my head that people were just teasing me, but still feeling hurt, afraid, and real rage at being treated that way. Since then I've been thinking more about the feelings that brought up or back to me and realized that those experiences probably explain a lot about who I am and the various political stances I've taken in my life.

At some points, the research has become less objective and all the talk has become a mere touch. Like when one woman told me about her little two year old boy being drowned in the septic tank out back and she "liked to never get over it. We all moved out of the house for about 15 months. I thought I never would be able to go back in there. But now it's okay and it feels more comforting. She had already lost a son in a miscarriage and that was very hard for her. When her second son died, she had another small girl baby, and felt that she couldn't really grieve for fear of hurting her daughter. Now she has three of the most beautiful daughters and she "has to be grateful for them," but she has had a tubal ligation because she just didn't want to take another chance. "I'll wait for grandsons."

Someone had already told me about traditions around death, how the family leaves the home, partly because of the sad memories, but also because of the fear that the spirit of the dead person would "catch" someone. After some length of time, there is the "opening of the house" and a witch-doctor is called in to "smoke" the house to make it safe and ready for the occupants to move in. At that time, the relatives can take any belongings of the deceased that they want, and if they don't want anything else, will turn it over to the other more distant relations to take what they want. Actually, I found out last night from one of the policemen that they had heard that I was here studying characteristics of "death" because of the way that people from this region pronounce the "th" as "f".

Perspectives on Disability and Deafness

Much of my discussion with people has centered around the notion of disability and deafness. Because of my work with American Indians who are deaf, I had anticipated finding "western" explanations for the deafness as well as "traditional" ones related more tribal world views and happenings. In most cases, I have found people to describe their deafness from a medical viewpoint. For example, one old woman I talked with was deaf in one ear and she also had failing kidneys and was on a waiting list for a transplant—at least until her family talked her out of it. She told me that when she was small, she had a lot of pus in her ears (chronic otitis media), which she believes to be the cause of her current hearing loss. Another old man I spoke with became deaf as a result of industrial noise. He worked for years in a wood mill on a station, and first started noticing his hearing becoming worse in 1956. Since then it has progressively gotten worse. Again, his view of deafness is pretty straightforward and medically based.

Most of the hearing loss I have encountered here has been the result of otitis media, and has been an acquired condition. The only incidence of profound sensori-neural hearing loss with an early onset I have found here in Doomadgee is in a 10 year old boy. His parents are obviously proud of him, and his father took pains to tell me what the boy is able to do that is similar to other children, for example, fishing because he watches carefully what to do, and turning somersaults like the others. His father was also pleased that his son can write his first name, although he had difficulty with his last name, but then his mother took over the pen and wrote it for him. When I asked the mother how her son became deaf she said that when she was "carrying him, I saw my girl runned down in the street, right here in front. I reckon I got a shock" and that is what caused deafness in her son.

Most of the people here do not use the tribal sign languages that they have, and the younger ones have forgotten the signs. They also do not use these signs to communicate with the people who have hearing impairment, but as with the 10 year old boy's family, they use a combination of Australian signs (taught by an itinerant teacher) and "home signs," some of which could be considered standard signs used by the tribe. Other people communicate with him using hand signs that are made up on the spot, but with which they profess a clear communication with the boy.

...some of the people I have talked with seem to view it as "natural" or at least an accepted part of life.

Another aspect of the research I have been doing has been to investigate the attitude toward disability prevalent in the communities. In most of the discussions I have had with people, the otitis media does not seem to be of great concern; in fact, some of the people I have talked with seem to view it as "natural" or at least an accepted part of life. I have gotten different comments from people concerning the presence or absence of pain with the otitis media and related conditions, but in general, people do not view the hearing loss related to it as a problem, and it is certainly not considered a disability. Some of the work done by Glenis Grogan, in Western Australia, has indicated that "disability" is usually viewed from the perspective of functional loss. As such, it can either mean a medical condition that has a significant impact on function (perhaps similar to our conception in rehabilitation of 'handicap'), or it can mean being separated from your family, or not having enough to eat. Here in Doomadgee, people do not seem to find otitis media and hearing loss to be a disability, although for the old man discussed above, his loss is certainly becoming a nuisance because he is having more trouble commu-

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nicating with his grand children and wife now.

Since being in Australia, I have come across only a few instances of genetic deafness, and also a very low incidence of sensorineural and profound deafness. There is a family group in the Western Desert region of Australia that reportedly has a number of deaf people in it (Ann Jacobs, personal communication), but no one has actually talked with the family about their conceptions of the hearing impairment. Ann's observation, though not fully tested, is that if the deaf individuals in the family are "literate" and trained in a vocation, then the deafness is not considered a disability, but it is if they have no training or significant role or function in the community. Ian Henderson is planning to follow up on the family to parallel the work that I have been doing as part of the fellowship from IEEIR. Also, in a week's time I will be moving on to Cairns which reportedly has a large educational program for the deaf, a substantial deaf community, and "3 or 5" Aboriginal deaf individuals who use sign language. My plan is to meet with them and follow up on the information I have gotten here in Doomadgee.

Most of the people I have talked with have maintained that people with disabilities are accepted in the communities without any discrimination. The most common response I have gotten is "they're just like anyone else, no need to treat them any differently."

Related to the perceptions of disability has been my interest in attitudes toward people with disability, in particular deafness. Most of the people I have talked with have maintained that people with disabilities are accepted in the communities without any discrimination. The most common response I have gotten is "they're just like anyone else, no need to treat them any differently." There are some notable instances of difference with this prevailing viewpoint, particularly from the people who have the disabilities themselves. For example, there was one instance in Western Australia of a person who was deaf feeling "embarrassed" about having a hearing impairment, including feeling "shy" about wearing a hearing aid and admitting to people that he doesn't hear well. Also in Western Australia, there was an instance of a man who had his leg amputated who kept refusing to wear his prosthesis. Finally some bright soul figured out that part of the problem was that the prosthetic leg was "pink"! After they painted the device to his natural color, he reportedly had no difficulty in wearing it. Also, several teachers here in Doomadgee have told me that many of the kids with hearing losses are reluctant to wear their hearing aids or FM units in the classroom. It appears that they don't want to be identified as "different" from their classmates. So, one possibility is that despite the statement from most people that people with disabilities are not the subject of discrimination or negative treatment, there remains at some level a lack of easy acceptance of either remediation or acknowledgment of the hearing condition.

One possibility is that within the community, the notion of differences or disability is not attached to deafness; but rather only within the "rehabilitation" domain is the differences pronounced. This would mean that intervention actually creates a "disability framework" that sets people apart. In fact, the struggle over intervention is one that almost every Aboriginal worker has talked about with me. There is a clear awareness that medical intervention is a "foreign" thing and most question the "ultimate good" of providing remediation and rehabilitation. And, in fact, much of the medical intervention given to the kids with otitis media does no practical good anyway. The question constantly arises about the pragmatics, not only related to changes of traditional life-style, but also for the use of medicines that seem to have no effect, the use of grommets or shunts, and surgery to correct perforated ear drums. All of the workers I spoke with, however, dealt with the dilemma by following their job expectations and providing the medical intervention.

There were other instances, however, that indicated that people with different physical conditions may be treated differently within the community. There was a strong attitude of "taking care" of people with disabilities, which almost certainly puts the person with the disability in an "unequal" capacity. The expectations for the 10 year old boy were much less than his brothers, sisters and cousins, and he was frequently allowed to stay home from school when the other children were all made to go. People with disabilities are often "just kept at home," and are protected. This latter phenomenon is not the only one that is common in America, but is also something that causes frustration among the Aboriginal Rehabilitation Officers (AROs) working with Commonwealth Rehabilitation Service case managers. In other words, the AROs expressed frustration at getting these protected and sheltered individuals "independent," though there was little discussion about the cultural values that are laden in the notion of independence.

Another instance of differential treatment was told to me by the old man with a hearing impairment from an industrial noise-induced trauma. When I asked about how people in the community communicate with him, and if they make a point to include him in communications, he said that people just tend to ignore him and don't try and let him know what is being discussed. I was told by others that, contrary to all descriptions about the importance of family and community involvement, he and his wife tend to isolate in the community. This phenomenon may be similar to reports of adventitiously deafened people in America who tend to become more socially isolated, both from friends and family, after the demands of trying to communicate with the hearing impairment become too taxing.

Other individuals reported that people with disabilities may be accepted by their families, but may tend to be "put aside" by the rest of the community. They may also be made the object of teasing within the larger community. Being put aside by the community is reportedly more common if the disability (illness or other condition) is perceived as the result of being cursed. This type of curse was widely described as being the result of having engaged in ways that break the tribal "law", perhaps having seen or done something that one should not have. Usually the result of having broken the "law" was extreme illness and death. In only one instance was deafness described as being the result of having

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been cursed. One woman told me a story of a man who was made "deaf and blind" by a curse. Several members of the community who were church members went to some "special" waters in the river (perhaps for a baptism?) and when the man came up from the water he began proclaiming "I can see! I can hear!" The other illness that was reported to be the result of some spiritual reason was leprosy, although none of the people I spoke with actually claimed to see someone healed from this disease. Because deafness was generally viewed as a medical rather than spiritual condition, deafness was not something one would usually contact a witch doctor (medicine man) for healing. A witch doctor would be consulted if you had been "caught."

There were several descriptions of the ways people could tell they had a curse rather than a regular illness. Sometimes the curse involved catching a mate. In this case, the way you know someone had put a spell on you was if a particular person's face continued to come unbidden into your mind. One person described this phenomenon to me as "you just can't stop thinking about that person, and you finally convince yourself that you are in love." But the relationships rarely work out, I was told, and there were numerous examples to support this. In fact, I met one Aboriginal woman in one community I visited, who I later learned "caught" her husband by doing the "doodah" process that she asked her grandmother to teach her. Now, after about two years (the usual period when the "spell" starts to wear thin) she and her de facto husband are having troubles.

Another story told me by many individuals was that one way to tell you are "caught" is if you are otherwise healthy, then suddenly become violently ill, or become ill at a particular time of the day, usually in the evening. There were numerous stories told to me about this type of occurrence, and for these problems people would seek the services of a healer. The healing process, therefore, is usually to heal illness caused by spiritual problems, someone causing a curse, not following the law, or from some more inner imbalance that needs spiritual remediation, rather than medical. One example of the types of problems caused by people not following the law have been told to me as well. Throughout my trip, there have been a number of people all over Australia who have told me about serious problems in one community. The stories about this community include reports of men having sex with children, men who are raping women, and homosexuality—all of these are behaviors in clear opposition to tribal law and natural order. Also, these behaviors were prophesied many years ago by some of the old, wise people in the tribe there. According to many of the individuals I talked with, the usual method of dealing with this type of behavior, punishment from the tribe, is not followed, partly because people are afraid of retaliation against their own families if they try and intervene. So in this case, the usual balance in the community has been disrupted, making the social network dysfunctional. People have not sought to right the order, or find healing for the community as a result.

In another community, because of the blending of tribes and clans by the missionaries (a common occurrence over Australia), there are people who are violating traditional practices concerning marriage. According to several people, despite teachings and cautions from elders and family members, some people are continuing to "stay with the wrong people." Because of this practice, children are born to these couples with disabilities including mental retardation, physical problems and sundry others. Although one woman said that she "reckoned the disabled children teaches them a lesson," they continue to live together and produce more children even though their parents try to split them apart and tell them the trouble they are bringing on themselves. When I asked one woman what her perception of the problem was, she said that the nature of the trouble "has nothing to do with medical science" but rather the fact that the couples broke the tribal law.

Probably the most insidious influence to destroy the balance in the communities has been the use and abuse of alcohol. Everyone I spoke with recognizes this as a problem, and attempts to effect changes are a constant part of all health workers' jobs. I met with several families with children who, in addition to other problems, had some degree of deafness as well. A common question was whether the deafness caused the other problems, such as behavior problems, enuresis, or "not knowing how to do things." In most cases, I surmised that fetal alcohol effect or syndrome was actually the source of all of the difficulties. Many of the children of people who drink excessively are "fostered out" to another family. Family Services seems quite involved in maintaining care for them. Significant attempts are made to find foster placements with Aboriginal people, usually with a relative in the same community, rather than with white families or in urban environments.

Attitudes Toward Rehabilitation Services

The view of rehabilitation varies widely according to individual perceptions. Some of the ARO's have mentioned that many people think of rehabilitation as being jail, alcohol treatment, or the "state forest," presumably referring to some juvenile detention work programs. The Commonwealth Rehabilitation Service is similar to the American structure for Vocational Rehabilitation in terms of expectations, goals and eligibility requirements. In various parts of the country, the ARO's have expressed some difficulty with recruiting clientele from among the Aboriginal communities, partly because of the lack of general awareness or shared negative perceptions about the services. A practice that has the most positive outcome has been using the ARO's as liaisons between the case managers and the Aboriginal communities. All of the ARO staff I spoke with said that a major part of their job was networking on a continual basis.

In most communities, rehabilitation activities are connected with medical services, and almost everyone has an opinion on the quality of care that they are receiving. In general, most of the Aboriginal people I spoke with were not satisfied with the level of intervention, but that view was very different from those expressed by Anglo people (not the professionals working in the field), who generally consider the level of services to be sufficient and, as is typical in American research reports, tend to blame the clients for "non-compliance, absconding, failure to cooperate." In my final report, the rehabilitation services will be described in detail, along with interview information concerning those services.

❖ Vocational Services/Employment Issues

❖ Rehabilitation at the Worksite and Employer-Based Transitional Work Programs for Injured Workers: A Study of Canadian and Australian Models

Donald E. Shrey, Ph.D., Associate Professor and Director of Disability Management, Department of Physical Medicine and Rehabilitation, University of Cincinnati Medical Center

Dr. Donald Shrey, Associate Professor and Director of Disability Management at the University of Cincinnati Medical Center, has conducted disability management research, training and consultation to business and industry since 1976. During 1992-1993, he was awarded a joint World Rehab Fund-IEEIR and World Institute on Disability IDEAS Fellowship to study Canadian and Australian disability management and transitional work programs in business and industry.

Canada

The Canadian component of the study included a combination of lectures, presentations, meetings and policy consultations with labor and management, government, insurers, educators, and rehabilitation professionals. Disability management seminars were conducted in Toronto, London, Parksville and Vancouver. Meetings and consultation activities were conducted with the Insurance Bureau of Canada, the Ontario Insurance Association, the Office of the Employer Advisor, Ernst & Young, Workers' Compensation Boards of Quebec, Ontario, British Columbia, and Alberta; the Injured Forestry Workers Association of Canada, the Premier's Advisory Council on Persons with Disabilities, HLRA Health and Benefit Trust, Medex, the London Disability Management Research Group, and Western Ontario University. Information was gathered from several employers, including MacMillan-Bloedel, General Motors Corporation, Cuddy Food Products, Ellis-Don Construction, Cominco Limited, Canadian Paper Workers Union, British Columbia Rehabilitation Society, several hospitals, and others.

The overall study revealed that, for the most part, Canadian business and industry has only recently gravitated toward rehabilitation at the worksite. Ontario's Worker's Compensation Board is faced with a $14 billion "unfunded" liability, as a result of uncontrolled workers compensation costs. Many of the cost problems appear to be directly influenced by political fluctuations - predominately, shifts in workers compensation schemes that reflect the policies and self-interests of labor-supported versus liberal industry-supported governments. Many employers, labor organizations and government agencies are gaining an appreciation for proactive rehabilitation concepts, such as "early intervention," "case management," "Individualized Written Rehabilitation Plans," and "on-site transitional work programs." Isolated initiatives from government appear responsive to employer needs and interests. For example, in Ontario, the "Rapid Reemployment Initiative" of the Office of the Employer Adviser reflects this agency's mission to develop employer advisory services in order to facilitate the development of early intervention and gradual return to work programs.

The Canadian Workers' Compensation System

The Canadian workers' compensation system operates throughout 10 provinces and 2 territories. All Canadian provinces and territories have exclusive state funds. Overall, Canada has about 10% of the population as well as 10% of the GNP of the U.S. Each Canadian province/territory has its own Workers' Compensation Board, which is mandated by provincial legislation. All Canadian Workers' Compensation Boards are exclusive, which means that the law requires certain industries to insure in a monopolistic provincial fund. Each Board has a Chairperson and at least two other members. Many Canadian Boards have changed from having all purpose boards to having appeal boards and corporate boards of directors. Each Canadian board has the power to examine, hear and determine all matters and questions arising under the Workers' Compensation Act. For example, the boards are guided by provincial Acts, which provide only basic guidelines for the boards to follow. Each provincial board formulates its own rules, decisions and orders. The Courts do not play a significant role in the day-to-day operations of a board.

In 1990, there were over one million work related injuries in Canada. Over 619,000 of these required time off from work. Each year, 30,000 Canadian workers suffer permanent disabilities. At any given time, about five per cent of all Canadian workers are away from work on long-term disability. The costs of Canadian workers compensation claims in 1990 was about $4.3 billion. The injured worker's claim is against the fund, not against the employer. The amount employers pay is determined by the type of industry they do business in, the dollar amount of their payroll, and by their past experience with workplace injuries. Experience rating further rewards or penalizes individual employers. Employers also benefit from the no fault insurance. When a workplace accident occurs, the board pays out benefits regardless of the fault of the accident. As such, workers cannot sue their employers or their co-workers, even if they directly caused the accident.

Many of the principles regarding benefits to workers are similar in both the Canadian and United States workers' compensation systems. Canada, however, has managed to arrange broad health insurance coverage of its entire population, to deliver, in general, adequate care, and to pay about 9% of GNP compared to 11% of GNP in the U.S., where 25% have inadequate coverage.

Many of the Canadian provinces appear to have used the Ontario Workers' Compensation Board as a general model, with certain differences and modifications. For example, the Vocational Rehabilitation Department at the British Columbia Workers'

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Compensation Board has the same hierarchy of objectives as Ontario and is committed to early intervention. Rehabilitation allowances cover the cost of retraining or education programs if those programs are considered necessary to overcome the effects of a residual disability. Discretionary payments can be made when wage loss benefits have been terminated for workers seeking employment or awaiting training. However, programs offered by the Canada Employment and Immigration Commission are considered before providing allowances. Typically, services provided to clients within most provinces include vocational assessment and planning, job readiness and placement assistance, counseling, skill development and employability assessment.

Most provinces have services for injured workers that feature an active case management system, functional evaluation units, a vocational/work evaluation program, some worksite and job modification programs, a job search assistance program, a vocational rehabilitation program, a training program, and specialized services (e.g., spinal cord or other severe injuries, industrial diseases, assistance for surviving spouses and dependents of deceased workers).

Provincial Services

In **Alberta**, a Rehabilitation Centre specializes in work hardening, a program designed to facilitate early intervention and early re-employment of injured workers. This program does not appear to have progressed to worksite rehabilitation. Alberta's case management strategy was adopted in 1989, whereby a case manager coordinates various Board services and helps ensure early intervention in physical, medical and vocational rehabilitation in cases involving more than 30 days lost time from work. The case manager establishes a rehabilitation/work return plan with the participation of the worker.

Saskatchewan offers specialized services, which include supportive counseling, technical aids, modification to the home/workplace, and personal care. Its Job Readiness Program, Employer Liaison Program, and Employment and Skills Development Workshop are directed towards jointly established and clearly focused employment opportunities for injured/disabled workers.

Manitoba features an Adjustment Program for injured workers, which addresses the personal, social or emotional difficulties that result from the injury. Specific services include social, supportive, financial and vocational counseling. Manitoba has a strong focus on vocational assessment and employment services, including a Job Finding Club, Individualized Marketing Service, Worksite Modification Services, and On-the-job Training Services. Manitoba's Information Systems Project measures key variables such as time between injury and vocational rehabilitation intervention, duration and cost of vocational rehabilitation involvement, types of vocational rehabilitation intervention, and employment status at time of case closure and in subsequent years. The Disability Prevention and Management Program in Manitoba is a model for other provinces for technical assistance and information dissemination to employers to address safety hazards at the workplace.

Quebec's Commission de la Sante et de la Securite du Travail de Quebec has programs quite similar to the other provinces. However, the Ergonomic Analysis Worksheet is a unique approach, which facilitates the return to work process among those with permanent functional limitations. The worksheet approach allows for the creation of a worker profile, company profile, comparison of worker capacities and job task demands, and selection of corrective measures.

Newfoundland's program includes the unique Self-Employment Assistance Program. This program is designed for workers unable to benefit from conventional rehabilitation services due to lack of education, lack of skills, age, limitations due to the injury, or the failure of conventional programs.

Employer-based disability management systems in Canada are emerging, as a result of the increased costs of workers compensation programs. For example, Cuddy Food Products in Ontario has developed a program which involves the participation of workplace safety and training personnel, health care professionals, worksite designers, ergonomists and engineers, and union representatives. Injured workers are brought back onto the line, either in a gradual return to work situation or in an alternative position. A team work approach reduces the chances of repetitive strain injuries by permitting the worker to move around the plant and perform an array of tasks that utilize different muscle groups. A company ergonomist addresses the needs of injured workers and assesses potential work station changes which prevent injuries from occurring.

Summary of the Canadian Study Outcome

This study has resulted in exciting opportunities for the exchange of information and resources between Canada and the U.S. The following activities are currently underway:

❖ 1. *Planning the development of a disability management newsletter for employers in the U.S. and Canada*, to be coordinated by the Disability Management Institute of Canada, the London Disability Management Research Group, Western Ontario University and Advanced Transitions, Inc.

❖ 2. *Training of insurance claims representatives* in the use of the Individualized Written Rehabilitation Plan, and strategies to utilize private rehabilitation services for case/medical management.

❖ 3. *Development of a rehabilitation counselor education program at Western Ontario University*, by exporting Kent State University's core accredited program and faculty resources, and making it available to private and public rehabilitation professionals, employer representatives and other Canadians. This program, once fully implemented, will facilitate the development of Canada's first graduate rehabilitation counselor training program within a Canadian university. It will also enable rehabilitation professionals to acquire Certified Rehabilitation Counselor (CRC) status, thereby influencing the professional development of rehabilitation counselors in Canada.

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❖ 4. *Development and implementation of the Disability Management Institute of Canada*, based in British Columbia. An initial government grant has support office space and associated costs. Business and industry is expected to provide substantial financial support of this disability management resource for employers. This institute will be designed to promote the ongoing exchange of research, publications, and other resources between Canada and the U.S. The Institute will pioneer new approaches to integrating/reintegrating Canadians with disabilities into the labor force. The mandate of this national Institute will be to increase the labor force integration and participation of people with disabilities through effective partnerships with business and labor, government, rehabilitation professionals and consumers. In carrying out its mandate, the Institute will pursue the following aims: **a)** Focus on reducing the human and economic costs (to disabled workers, businesses, labour, governments, consumer organizations and society at large) that result when effective job integration/reintegration measures are not in place. **b)** Create strategic, long-term partnerships for an effective and coordinated approach to the challenge of job integration/reintegration. **c)** Forge international alliances to monitor and develop new approaches toward the challenge of job integration/reintegration, and ensure that these new approaches are viable within the context of the global economy. **d)** Ensure that employers seeking to comply with employment equity requirements are provided with an effective means of doing so. **e)** Focus on developing return-to-work and disability management programs, based in the workplace, that will begin the job reintegration process as soon as possible following the onset of the worker's disability.

❖ 5. *Development of industry-based demonstration projects* to promote transitional work programs for injured workers. Information from Dr. Shrey's pioneering efforts in the U.S., regarding disability management policies, procedures, and joint labor-management supported models, are currently being introduced at McMillan Bloedel (one of Canada's largest employers). A variety of activities are currently being planned to introduce model program concepts among other Canadian employers.

Australia is in the midst of a virtual revolution in disability management. Although each Australian state differs in its workers compensation statutes and corresponding schemes, most states are moving rapidly toward worksite rehabilitation initiatives.

❖ 6. Dr. Shrey and Dr. Michel Lacerte, M.D., Director of the London Disability Management Research Group (London, Ontario), have collaborated on an edited book, *Principles and Practices of Disability Management in Industry*, to be published by PMD Publishers Group, Inc. in the late fall of 1993. This book includes over 700 pages of contributions from over 20 multidisciplinary experts in disability management from North America.

Australia

Dr. Shrey completed a three week visit to Australia, as well as one week in New Zealand. He delivered a keynote address to over 500 participants at the Second Annual Rehabilitation Conference on *Rehabilitation: Reducing the Cost of Injury and Disability* (May 12-14, 1993) in Sydney. He also served as moderator of an eight-speaker symposium on worksite rehabilitation.

The study included visits to facilities of the Commonwealth Rehabilitation Services, meetings with Comcare (Services for injured Commonwealth employees), and with management representatives from the Workcover Authority in Victoria. Various meetings were held with managers of private rehabilitation services, insurance representatives, and others.

Dr. Shrey completed an interview for *The Australian*, Australia's national newspaper, and he participated in a radio talk show hosted by Elaine Harris, a disability consumer and advocate. Information was obtained from visits to a variety of employers, including a Sydney shipyard and Melbourne's Smorgan Steel Company. Information was obtained from Ford Motor Corporation of Australia, Procter & Gamble, and others. The study included lectures at Latrobe University in Melbourne, meetings with several rehabilitation counselor educators and information exchange sessions with government officials.

Australia is in the midst of a virtual revolution in disability management. Although each Australian state differs in its workers compensation statutes and corresponding schemes, most states are moving rapidly toward worksite rehabilitation initiatives. Surprisingly (and to their credit), the Australians have not embraced hospital-based work hardening services, as rehabilitation professionals and others have in the U.S. Instead, new initiatives and legislation (e.g., Workcover in Victoria) require employers to establish formalized work return programs at the worksite. Such programs are typically designed for injured workers with 20 or more days of lost time. Thus, early intervention and on-site rehabilitation services are recognized and appreciated. Private case management services, as typically provided by rehabilitation counselors and occupational therapists, have been nearly eliminated by the new Workcover scheme. Instead, employers are required to designate an on-site rehabilitation coordinator who will assume many of the roles otherwise performed by external case managers.

Unfortunately, much of the worksite rehabilitation rhetoric among state workers compensation administrators and employers has not become a reality. Government officials appear somewhat unprepared to offer technical assistance to employers, with respect to the development model of on-site programs. Employers lack knowledge and skills for disability management program development. There are a few exceptions, however. Dr. Shrey observed that the disability management program at Ford Motor Company has features strikingly similar to *Honda of America's* Transitional Work Program, recently developed by Dr. Shrey in Ohio. Both programs include job analysis and on-site functional capacity evaluation components. Both feature on-site therapeutic monitoring, conditioning, safe work practice education, joint

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labor-management committees, and program time parameters of approximately eight weeks.

Smorgans Steel Company in Melbourne featured an on-site case manager, who functioned as an internal disability management team member, with liaison responsibilities with community treatment providers and other rehabilitation resources. Contractual therapists have been involved on-site and the company has identified modified duty options for injured workers. An unusual element at Smorgans was the presence of a non-medically trained acupuncturist with a homeopathy orientation, providing treatment to injured steel workers. He has become and accepted member of the company's rehabilitation program over the past 3 years.

Rehabilitation Counselor Education is a relatively recent development within Australian colleges and universities, and professional development and credentialing is within its infancy stages. (Readers may want to consult the excellent IEEIR study report of Dr. David Hershenson regarding Rehabilitation Education in Australia). Injured worker case management services are predominately provided by nurses and occupational therapists, who have acquired on-the-job training in case management skills. One occupational therapist with Industrial Rehabilitation Service (a private rehabilitation service company) provides both case management and on-site therapy services to injured workers at Ford Motor Company and other employers. This is a model worthy of consideration for the U.S., since injured worker rehabilitation requires an integration of case management coordination and on-site therapeutic interventions in transitional work programs.

Summary of Study Outcomes

❖ 1. A formalized training program in disability management skills for employers has been developed and utilized among Queensland employers over the past three years. This training program was shared with Dr. Shrey to be modified for both U.S. and Canada's business and industry.

❖ 2. Dr. Shrey has been invited to contribute an article to the Bulletin, the professional journal of the Australian Society of Rehabilitation Counsellors. He will also collaborate with Andrew Remenyi of Latrobe University, on an edited book regarding disability management in Australia.

❖ 3. Ongoing informational exchange activities have been initiated with Commonwealth Rehabilitation Services, Industrial Rehabilitation Services, the Workers Compensation and Rehabilitation Commission of Western Australia, Latrobe University, and the Accident Compensation Commission of New Zealand.

❖ *Vocational Rehabilitation Development in Hong Kong: A Cross-cultural Perspective* *Chow S. Lam, Ph.D. Associate Professor and Director of Rehabilitation Psychology, Illinois Institute of Technology, Chicago.*

Dr. Lam's study visit in Hong Kong was conducted during January, 1991. Then in August 1991, Dr. Lam was invited to present his preliminary findings at an international conference. The purpose of the study visit was to understand vocational rehabilitation development in Hong Kong and compare its practices to those of the United States.

As an IEEIR fellow, Lam found that Hong Kong's vocational rehabilitation development models after the United States with minor influences from British practice. Hong Kong vocational rehabilitation movement starts with medical rehabilitation and gradually expands to vocational and psychosocial rehabilitation. The expansion is attributed to rapid economic growth during the past twenty years. However, the 1997 political uncertainty has taken its toll on both the economy and human resources and halts the growth of rehabilitation.

The unique sociocultural values and beliefs of Hong Kong people influences the treatment of people with disabilities. Lam found that Western culture tends to be preoccupied with individual freedom (individualistic orientation) and the Chinese culture, under the influence of Confucianism, tends to be preoccupied with social order (collective orientation) (Bond & Hwang, 1987; Ho, 1987). Confucian philosophy advocates the virtue of sacrificing individual needs for the good of the group. One who does not meet his or her share of family obligation is subject to a significant amount of shame and guilt feelings.

For most Chinese families, life is presumed to be unalterable and unpredictable, requiring a designation to external conditions and events over which they have little or no control. Accepting this fate, human suffering is part of natural order. Maintaining inner strength under all the circumstance is considered by Chinese as an expression of dignity (Chan,1986). Consequently, Chinese disabled persons tend to resort to their family for support before seeking help from medical professionals. Quite often there was a substantial delay before professional help was sought. For psychological problems, Chinese tend to turn to their families and friends for support and not to seek any professional help at all.

Another area Lam noticed a great difference between Chinese people and the Americans is their attitudes towards counseling. Chinese people tend to distrust counseling. Chinese people often have difficulty expressing their emotions in clinical situations because they tend to view explicit expression of affection and the complaining of worry, despair, or pain as a sign of weakness. The Chinese patients may expect an "authoritative" doctor to detect physical and psychological disorders from "non-verbal cues", so that the patient does not need to make elaborate verbal complaints. The Chinese expected their counselors to be more directive and authoritative, and they may be less inclined to approach professional counseling services for solutions to their psychological problems.

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Implications for American Rehabilitation

From his study visit Lam noticed several implications for American rehabilitation. Some of the unique Chinese values and beliefs could have direct impact on rehabilitation practices. In order to work with Chinese American clients and their families, American rehabilitation personnel have to understand the "shame and guilt" complex of the Chinese culture. As pointed out by Chan et. al (1988), a particular type of disability may influence a family's willingness to encourage its disabled member to become active in the public (e.g., to find employment), or to remain under their care. Chinese tend to be more positive towards people with physical disabilities than mental disabilities. Chinese Americans with psychiatric problems may not seek professional help at all for fear of the stigma repercussions. Case finding and subsequent confidentiality may be particularly important in working with American Chinese clients.

Research has found that although Chinese Americans are quite resourceful in utilizing their network of family, relatives, and friends, they are not as effective or knowledgeable about using social service networks, and are often intimidated by bureaucracy (Leung, Nagasawa & Quan, 1979). As a result, many Chinese Americans with disabilities who are employable and could potentially benefit from vocational rehabilitation services continue under the care of extended family members. Outreach and case finding activities could be conducted in conjunction with local Chinese cultural organizations.

The Chinese tendency to accept traumatic events and suffering as a fact of life may help them adjust to their disability more quickly. Such quick adaptation may be mistaken as denial; therefore, rehabilitation counselors should be sensitive to Chinese peoples' particular adjustment process and should not follow the traditional "stage adjustment model" when working with these clients. In rehabilitation counseling, the need of some Chinese clients for direction and advice early in the counseling relationship may require a counselor to conclude the initial sessions with concrete suggestions. The use of the first two or three counseling sessions to specifically meet the needs of a culturally different client for direction and structure may be an effective approach.

Since many Chinese people are less prone to verbally express emotions, these clients may benefit from role modeling to learn appropriate ways of revealing their feelings in counseling. It is also helpful to instruct the clients about the benefits of emotional expression in their counseling process. Frequently, the lack of emotional expressiveness is not a sign of resistance, but only that the client does not know what is expected. Therefore, if counselors would like to elicit more emotional expression, they may have to provide demonstration, help clients role play some of the behavior, or even help clients build a list of vocabulary used to express a range of emotions (Chan et. al, 1988).

Although it is difficult to generalize from one socio-cultural setting to another, cross-cultural comparisons can sometimes shed new light on how our society works. Analysis of Hong Kong's policies of rehabilitation will help U.S. vocational rehabilitation personnel to reach decisions about the usefulness of such approaches in their own work.

❖ Mental Health/Psychosocial

❖ Can Mental Health Service Provision in Developing Nations Provide Ideas for Rural America? The Example of Kenya

Pauline E. Ginsberg, Ph.D., Utica College, Syracuse University

Janet Fitchen's (1981, 1991) descriptions of rural life in upstate New York[2] reveal the effects of economic and social change and analyze the inevitable stress they place upon family structures. The situations she describes are ones in which, just as the traditional strengths of extended family solidarity are stretched to their limits and the need for outside services increases, outside services themselves are reduced, consolidated, or centralized in urban areas. Consolidated schools, for example, require considerable travel for rural children. As a result, informal development of peer group support from school mates cannot occur. Churches often merge, requiring further travel and/or they gain new members who are relatively more affluent and culturally different ex-urbanites among whom rural people do not feel comfortable. The country doctor has been replaced, if at all, by the small town medical center. Small businesses falter and fail, move to town or, in some areas, become transformed into boutiques which serve summer residents and tourists. In sum, as the need for rural services has grown, their supply has not. Nor has affordable public transportation allowed the rural poor to take advantage of services in urban areas.

...both developing and developed nations share a need for new approaches to psychiatric rehabilitation characterized by economy, efficacy and maintenance or establishment of skills of daily living in a normalized, non-restrictive environment.

Even if transportation were available, however, as the mental health needs of rural people are different from those of their urban counterparts, so must be the interventions of service providers (Keller and Murray, 1982). For example, linkage between mental health and other human services is particularly crucial if families and individuals are to be maintained in their rural environment (Murray and Keller, 1991). Nor have our models been entirely satisfactory, even with the urban populations for whom they were designed (see Anthony, 1977); while achieving some remarkable success, they have been able to serve too few at too high a cost (Murray and Keller, 1991). This being so, might it not be possible that models being applied in other societies be of use here? Might it not be particularly the case that those developed in nations which are still largely rural could be adapted for use in rural America?

One African model implemented at Aro, Nigeria (Lambo, 1964) has elicited some interest in the U.S. Meant to serve those who live a traditional rural life-style through integration of western medicine with traditional healing and community support, rehabilitation villages give psychiatric patients the opportunity to participate in village life and maintain traditional skills and activities of daily living during a period of recovery or rehabilitation from major psychiatric disorders. Yet in the face of increasing industrialization, this model is of limited usefulness, even in Africa.

Thus, both developing and developed nations share a need for new approaches to psychiatric rehabilitation characterized by economy, efficacy and maintenance or establishment of skills of daily living in a normalized, non-restrictive environment. Perhaps the community based rehabilitation programs developed in Kenya can provide information about where to start. To that end, this paper will describe (1) how Kenya's community based rehabilitation services have been organized, (2) how psychiatric rehabilitation was or could be integrated within such services, and (3) some of the factors that doomed initially successful programs to failure. In addition, it will also discuss briefly some of the needs which would have to be met and some of the barriers that can be expected if we were to try to implement similar services in rural North America.

Kenya

Kenya, East Africa is located on the Indian Ocean south of Sudan, Ethiopia and Somalia, east of Uganda and north of Tanzania. A former British colony somewhat smaller than Texas, it became independent in December, 1963. The population is approximately 24 million, half of whom are under 15 years of age and 80% of whom are rural. The 40+ ethnic groups speak a variety of languages, but are unified by the national language, Kiswahili, and the official language, English, which is the language of instruction in secondary schools and universities.

Although since 1980 Kenya's psychiatric services have been in the process of rapid decentralization (Ginsberg, 1991), comprehensive psychiatric services are not yet readily available to most rural individuals. Nevertheless, since 1987 when psychiatry was included in primary health care (PHC), training in medical follow-up and management of psychiatric emergencies has been part of the training of PHC teams dispatched to rural areas. While PHC has had a great role in prevention, it has not, however, been sufficient to provide for rehabilitation of the chronically impaired— psychiatric or otherwise. Therefore, the question is being asked: Can community based rehabilitation (CBR) programs be developed either in conjunction with PHC or separate from it which will assist those who require psychiatric and/or physical rehabilitation?

To answer the question with regard to psychiatry, a month long study-visit was arranged during August, 1992, at which time four of Kenya's seven CBR programs were visited.[3] This visit built on

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	Successful programs	Unsuccessful programs
Funding	Partially self-supporting Multiple funding streams	No funds generated locally Single funding stream
Administration	Participatory Fiscal management skills developed at program site Responsive community needs and input	Professional Fiscal management off-site or by donor Inflexible regarding program content
Staffing	Volunteers from a cohesive social unit Role blurring, team approach Desire to give the program away by training community Duties include community organization	Volunteers not used or strictly task oriented Discipline chauvinism Professional staff attitude of classism Duties limited to professional services
Service Provision	Community based, mobile, accessible Staff takes service to client Clients included in decision-making Include adults	Site based, static inaccessible Client comes to staff for service. Excluded from decision making Limited to children
Relationship to Community	Community organization of great importance Involves community in routine decision-making Community shares financial burden	Relates only to donor/ funder. Only seeks community participation in emergencies Community excluded from financial involvement
Relationship to Other Programs	Integrated service provision and coordinated planning	Separate, distinct and independent

Table 1 Distinctions between successful and unsuccessful CBR programs

three previous visits. In Kenya in 1985, 2 weeks as a tourist, 1989-90, 6 months sabbatical, teaching at the University of Nairobi's Department of Psychiatry and studying decentralization of psychiatric services and 1991, 1 month visiting friends and planning the 1992 study-visit.

Kenya's Community Based Psychiatric (CBR) Services

Of the 4 programs visited, the oldest was located in Kibera, a poverty stricken area of the capitol, Nairobi and was limited to children with physical disabilities. Another, also limited to children with physical disabilities, was located in Malava, a rural district of Western Kenya. Two others served both children and adults. One of these, at Kibwezi, provided services to a mixture of small towns and rural areas. The other, based in Kisumu, Kenya's third largest city, targeted surrounding small towns and rural areas. All were funded by a combination of at least one international donor plus Kenya's Ministry of Health.[4] Only the one based at Kisumu included mental health among its services. It had done so from the beginning through inclusion of a psychiatric nurse in its combined PHC/CBR team. The team based at Kibwezi, however, was receptive to inclusion of mental health, regarded counseling as a necessary component of all rehabilitation efforts, and had requested inservice education in that skill area prior to our discussion.

One characteristic integral to CBR programs and shared by all programs except that at Kibera is use of a corps of permanent volunteers trained in diagnosis and treatment of common conditions and recognition and referral for less prevalent problems or those requiring professional intervention. These volunteers are selected from the community and, in successful programs, by the community. Since the demands made on volunteers are rather great, there is the persistent problem of retraining a full complement of volunteers and of providing training for replacements when volunteers burn out or enter paid employment. Successful programs not only do this, but also integrate the volunteers into the pre-existing volunteer social unit.

All programs also have a small team of professional health workers and a paid executive director who is either a health care professional or a community member with on-the-job training. In successful programs, this is a high energy individual with credibility in the community and involvement in it. It is not an individual who stays in the office and works more with papers than with people.

Finally, all programs have a community education component. Successful ones emphasize this function more heavily than others. Whereas all seek to educate teachers with regard to mainstreaming, successful programs also educate local crafts people to make and repair aids, families and neighbors to assist in training and adapting equipment for individuals with handicapping conditions, clergy, politicians, school children and citizens' groups to engage in health promoting life-styles and disease prevention activities and to recognize, understand and refer those in need of specialized assistance.

With respect to other characteristics, the four CBR programs studied easily allow an observer to draw distinctions between successful and unsuccessful. Five examples are shown in the chart on this page.

Applications to North America

What needs and barriers does an American model face that may be different from that in Kenya? One of these is financial and administrative. While Kenya does have governmental administrative units comparable to our own, unlike those in North

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America, none of these has fiscal or administrative power outside of that of the central government. That is, only the central government has the power to tax and the power to effect major changes in policy. Therefore, the need to affect and integrate policies and funding streams at all levels of government offers us a different type of challenge.

Cooperation across administrative lines is difficult in both places. The CBR program operating out of Kisumu, for example, works with matters that might otherwise be assigned to the Water Authority, the Ministry of Livestock, the Ministry of Education, the Ministry of Social Services and Culture and the Ministry of Health and well as donor agencies which must secure government support. A U.S. counterpart might involve Cooperative Extension, public and/or private health facilities, charitable foundations, United Way, a university separate from that with which Cooperative Extension is affiliated, public schools, county and state government, county social service, 3rd party payers (and their utilization review arms), public pressure groups, the Public Health Service, the Social Security Administration and NIMH. Maintaining fiscal and administrative responsibility in a way that is cooperative rather than competitive and which gives substantial control to the community has all the makings of a nightmare. Yet, for many of these organizations, ignoring them or their interests would be an even greater threat to program success. Competitiveness in our relatively resource-rich environment can be a hazard which is absent in cases where the PHC/CBR program is the only social service game in town.

Assuming, however, that territoriality can be overcome and cooperation secured, what other problems should be considered? While several aspects of the conclusions based upon the chart above will seem obvious to North American service providers, I would like to caution against their too-facile dismissal as self-evident. Accessibility, for example, does not refer only to whether a building is equipped to cater to individuals with physical handicaps. It also takes into account whether there is sufficient parking and whether service hours are convenient to accommodate client school and work schedules. For those in large cities with significant public transportation it includes the distance from bus or subway stops. For the non-affluent living in rural areas where maintaining a working automobile with fuel in it is all too often the only alternative to staying at home, provision for mobility may be the only guarantee of accessibility.

Similarly easy to read and dismiss is the information about use of professionals and volunteers. In the 70's, the team approach with significant role-blurring and the use of community volunteers (or even paid para-professionals) were common. Since then, except for emergency telephone services and some alternative services (e.g. women's shelters), both have faded into the background and mental health care has been reprofessionalized. The above information suggests that we may wish to reconsider. So, in fact, does the clubhouse model of psychiatric rehabilitation (Anthony, 1990). I would also submit that in the isolated and isolating rural America which Fitchen (1981, 1991) describes, the opportunity to be a volunteer in a program which provides social opportunities, esprit de corps, and outside recognition is health promoting for the volunteer as well as the service recipient. Moreover, volunteers may provide the key to acceptance in a closed community.

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Endnotes

[1] This paper was prepared for the National Association for Rural Mental Health, June 20-24, 1993, Lincoln, NE.

[2] Although Fitchen writes of central New York, my current home, her descriptions vividly evoke images of eastern Nebraska and memories of my experiences in the rural counties served by Omaha's Immanuel Community Mental Health Center in the early 70's as well.

[3] The initial (1989-90) research was conducted under the Government of Kenya research permit OP.13/001/19C 70/7 and supported by Utica College of Syracuse University and the Department of Psychiatry of the University of Nairobi. The subsequent (1992) study-visit was funded by the International Exchange of Experts and Information in Rehabilitation, a project of the World Rehabilitation Fund and the University of New Hampshire's Institute on Disability, and by Utica College of Syracuse University. The Division of Mental Health of Kenya's Ministry of Health was invaluable on both occasions and served as the study-visit host agency without which the research would not have been possible.

[4] For an extensive description of each program, a longer version of this paper is available from the author.

[5] Successful programs could be easily distinguished from unsuccessful ones on the basis of client volume, staff attitude and funding.

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❖ Development of an Integrated Healing Model to Address the Mental Health Crisis Among Khmers in Cambodia and the U.S.

Sharan Elizabeth Brown, Ed.D., Research Associate, University of Washington
Lane Anthony Gerber, Ph.D., Seattle University

Sharon Brown and Lane Gerber's study/visit had two primary objectives. The first was to introduce Khmer physicians, psychologists, Buddhist Monks, and Khru Khmers (Traditional Healers) to the western theory of psychopathology and Western therapeutic approaches and rehabilitation interventions. The second objective was to obtain information on traditional Khmer approaches to mental health problems and how they may be addressing those problems currently. Both Brown and Gerber work with Cambodian refugees in Seattle.

Personal Reflections, Sharon Brown

There were two types of learning that occurred for me as a result of this study-visit. The first was the expected—increased cognitive understanding of Khmer attitudes towards mental health issues based on the substantive information gleaned from both formal and informal data gathering. The questionnaire data as reflected in the results has been described above and, although extremely limited, did provide me some insight into current Cambodian beliefs and practices in this area. However, it was the spontaneous meetings and interactions with people that taught me more about the Cambodian approach to all difficulties and made me sensitive to the need to understand in greater depth the cultural attitudes towards resolving problems. Specifically, this recent visit to a volatile Cambodia taught me something about the Cambodian attitude and approach to situations outside of their control. The western approach to a "helpless" situation is more likely to be action in an attempt to change the situation—if at all possible. Generally, I observed an opposite reaction among Khmers to such situations—i.e., passive acceptance which seemed to go beyond that commonly demonstrated by traumatized groups. This culturally ingrained passivity seemed to me to be reflected not only in the Khmer deference to the head of the family and government leaders, but also to all authority figures including western professionals. It also struck me that the Buddhist belief in the inevitability of one's fate was perhaps another example of this passive acceptance of one's current experiences in such a way that changing that current reality was not a high priority.

Doing research and attempting to teach in the midst of anarchy was an experience that taught me the importance of flexibility, accommodation, realistic expectations, patience, and humor. I have learned that no one can prepare for all contingencies and that knowledge comes in many forms, some of which are unexpected and perhaps uncomfortable.

If the historical Khmer response to situations outside of their control—whether it be military invasion or mental health problems—has indeed been a learned helplessness, any helping model with a goal of teaching new behavior must focus on modeling and teaching alternative responses which may provide a greater sense of power and control. Cambodians have experienced innumerable sufferings. Whether their heritage and values have some part to play in their victimization is not addressed here. However, it seems apparent to me, that victimization and exacerbation of mental health problems will continue among Cambodians if they are not offered opportunities to develop new behaviors. Given their cultural heritage, although traditional healing approaches may help and need to be considered as part of a holistic approach to service delivery, skills such as self-determination and problem solving may be equally important.

However, it is also the reality of life for Cambodians that assertive behavior is fraught with danger. An example of this was the recent assassination attempt of a political dissident in Phnom Penh. Challenging the status quo is not a culturally valued behavior nor positively reinforced and this resistance to tampering with the traditional institutions seems to have followed Cambodians to the United States. At the Refugee Clinic this is poignantly demonstrated by the many women who are victims of domestic violence and get no community support for confronting their spouses or separating from them. Rather, there is a cultural expectation that the family will remain intact regardless of the dynamics between family members. Women who "suffer" are considered strong and there is value in suffering in silence. Therefore, albeit modeling different behavior would seem to be a valuable intervention, there is an ethical consideration as to it's appropriateness—either in Cambodia or within the Khmer-American community in the United States.

In addition to this more "academic" knowledge, I learned invaluable psychological lessons concerning the realities of conducting research and teaching in a country that is barely functioning and in the midst of—at times—chaos. This awareness seems important not only personally, but also because of the impact such an environment can have on future work in Cambodia and in similar countries experiencing social and political unrest. Doing research and attempting to teach in the midst of anarchy was an experience that taught me the importance of flexibility, accommodation, realistic expectations, patience, and humor. I have learned that no one can prepare for all contingencies and that knowledge comes in many forms, some of which are unexpected and perhaps uncomfortable.

Implications for the U.S., Lane Gerber

In combination with the results of talking with the native healers, monks, physicians, Canadian physicians, and medical anthropologists, the teaching and the giving and discussing of these questionnaires emphasized the way that Cambodians are willing to accept things the way they are, are expected to act submissively before authority, need smooth interpersonal relations, feel overwhelmed and helpless in the face of their losses and pain, emphasize the safety and security of home and immediate family,

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and feel considerable shame at any feeling or psychological experience that seems out of the ordinary. Therefore they especially do not want to reveal anything of the sadness or anxiety or angry outbursts or difficulties with remembering and concentration that are some of the hallmarks of PTSD that so many of them seem to have. This brought home to me the importance of establishing in the United States and in particular at the refugee clinic where I am involved, treatment and training modalities that fit with this kind of mindset, especially this kind of mindset that is now in a culture that values behaviors and attitudes very different from their original ones. For example, if Cambodians, especially those from the countryside who are now in the U.S. value home so highly, and are so submissive and passive (by American standards) in the face of authorities like health professionals, perhaps one option that would be useful for them is to have psychologically trained laypersons go into their homes to deal with crises that arise when a letter from the welfare office or immigration bureau causes their psychological symptoms to precipitously rise. In this regard some modeling and training might be useful in showing and teaching them that there are ways that they can cope with these and other difficult daily life occurrences in our culture rather than depending solely on getting some more powerful American professional or patron to take care of these issues (which also keeps themselves in a subservient position).

In addition, the importance of the nuclear family in the life of the individual is clearly very important. Family is a potential resource for help as well as a group that one must shield from any shame. Accordingly it is clearly important for the family to be involved at some level with whatever therapeutic help the refugee clinic patient receives in order for the family to support and understand treatment efforts—and for the patient to know that the family accepts their problem and the subsequent treatment.

Getting a deeper sense of issues of power and authority and shame and respect have, I believe, enabled me to be better understood by (as well as to understand better) the patients with whom I work.

Finally, understanding even more vividly the Cambodian reluctance to discuss psychological issues especially with people with whom they are not very close, and the Cambodian expectation that treating people have the power to heal and that patients are passive and given to by those "with the power" has already made a difference in my dealings with patients at the refugee clinic here. It is easy for non-Cambodian health professionals to become angry and frustrated by what they perceive as the "passivity" and "non-cooperativeness" of Cambodian patients. Alternately it also is easy for these same non-Cambodian health professionals to do "too much" for the Cambodian patient who has suffered so much trauma and whom one can see as "too hurt to be able to help themselves at all." Getting a deeper sense of issues of power and authority and shame and respect have, I believe, enabled me to be better understood by (as well as to understand better) the patients with whom I work. I seem to be able to talk with them in ways that are closer to their experiential world as well as be better able to differentiate between the effects of trauma and the cultural mindset of patron-client relationship. As paradoxical as it sounds, I have begun to act more like an authority with them and at the same time have been better able to enlist their help in working with me in their treatment. Moving toward this deeper understanding hopefully will continue to help me and others with whom I work and train—and thereby help the patients.

❖ *The Applicability of Morita Therapy (as Used in Japan) to the Pyschosocial Rehabilitation of Persons With Psychiatric Disabilities.*

Irvin D. Rutman, Ph.D., President, Matrix Research Institute, Philadelphia, Pennsylvania

For over thirty-five years Dr. Rutman has been actively involved in psychosocial rehabilitation (PSR). He became director of Horizon House in 1956. Dr. Rutman founded Matrix Research Institute in 1973. The study-visit is consistent with Dr. Rutman's career-long interest in developing new methods and models for providing effective rehabilitation programs for persons with mental illness, evaluating the effectiveness of these models, and promulgating the use of these models that have demonstrated effectiveness with this population.

During April and May, 1993, a Fellowship award from IEEIR enabled Dr. Rutman to conduct a study-visit to Japan to investigate the applicability of Morita psychotherapy principles and methods to psychosocial rehabilitation (PSR) services for persons with psychiatric disabilities. Since there are some 2,000 facilities providing PSR services in the United States and since there are many commonalties between the underlying principles of PSR and Morita therapy, there seemed reason to believe Morita approaches could usefully be incorporated into PSR methods.

Rutman made arrangements with four Japanese professionals to serve as "hosts" for his study visit. Three were psychiatrists, of whom two (Dr. Ohara and Dr. Kitanishi) were nationally recognized leaders of the Morita Movement, and the third (Dr. Semba), the director of a psychiatric hospital; and the fourth host, (Mr. Ideda) was the director of research of a comprehensive rehabilitation facility.

Rutman's study-visit began with attending the Second International Congress of Morita Therapy, a four day meeting held in Fukuoka, a city on Japan's western-most island, Kyushu. Over 250 participants presented papers and discussions regarding expanding uses of Morita therapy in Japan and throughout the world. Groups now being served by Morita-styled approaches include neurotics, psychotics, substance abusers, persons with eating disorders, AIDS victims, persons with terminal illness and others. In addition to Japanese professionals, the conference attracted presenters and participants from China, Taiwan, Aus-

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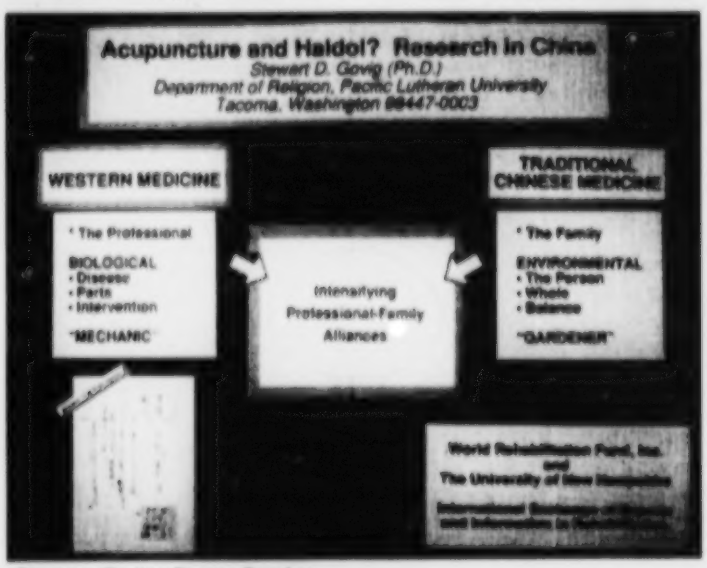
tralia, Europe, Canada, and the United States.

Following this conference, Rutman had arranged for day-long meetings with each of his hosts, to discuss current treatment and rehabilitation methods, Morita therapy and PSR, and to further steep himself in the mental health delivery system of Japan. These meetings took place at the National Institute of Vocational Rehabilitation, in Chiba, a suburb of Tokyo; at the Hamamatsu School of Medicine and Hospital, in a city about 100 miles from Tokyo; at the Chiba Mental Hospital; and at the hospital of the Jikei University, in a community about 30 miles from Tokyo. Communication generally went well, particularly since three of the four settings there were Japanese staff persons who had spent considerable time in training and/or employment in the United States and who served as translators. He also conducted seminars (one formal presentation at the NIVR, two informal presentations with staff members of the Chiba Mental Hospital and the Hamamatshu University Hospital) in which he described emerging trends and developments in mental health and rehabilitation occurring in the United States.

❖ *Health Professionals, Families, and Mental Illness: Toward a Western and Traditional Medicine Collaboration Model*

Dr. Stewart D. Govig, Professor of Religion, Pacific Lutheran University

From behind the ancient Wall and her attention to River and Peace, today China launches space satellites and has become a major player in international politics. In the next century, will more people speak English in China than in the United States? What will it mean to have a 1.2 billion population trading partner and competitor? With the exploding modernization of the People's Republic economy as a setting, the researcher sought rehabilitation connections between traditional Chinese medicine (TCM)—a practice thousands of years old—and modern Western methods. He found that in China the family was never blamed for causing the illness in any way; to the contrary, it was an assumed ally and indispensable for both diagnosis and treatment. In America we still speculate about family-as-allies potential. The family in China, however, is more isolated. No public National Alliance for the Mentally Ill (NAMI) activity is evident; to begin an organized effort for families to make contact for mutual support would be of great benefit. Someone in China should write an equivalent of E. Fuller Torrey's *Surviving Schizophrenia: A Family Manual* to get the ball rolling.



Stewart Govigs Poster Session

The term "model" is frequently used in the physical sciences. In considering something beyond direct experience a physicist, for example, might use familiar objects—colored billiard balls to provide reference points. Yet constructing an ascending spiral tree-like arrangement of colored balls is not intended as a replica of a DNA molecule; rather, it provides conceptual tools and vocabulary for speculation. In his *Models of the Church* (New York: Doubleday, 1974) Avery Dulles divides "explanatory" constructs (architectural scale models) from "exploratory" (teaching and research) ones. Beinfeld and Korngold's *Between Heaven and Earth: A Guide to Chinese Medicine* distinguishes the doctor as mechanic in Western medicine, and the doctor as gardener in the East.

Combining the strengths of each underlies the philosophy of New Life Farms, an exploratory interdependent group model resembling the Kibbutzim communal farms in Israel and the Amish agronomy seen in America. At New Life, soil and plant scientists attack weeds and parasites which hinder growth. They also research loam and sprouts to enhance production.

In hospitals and other settings, mental health professionals—psychiatrists, psychoanalysts, psychologists, psychiatric nurses and social workers—apply "high tech" skills and medications to confront acute episodes of illness. The immediate goals are (1) to plant the seeds, that is, cure by removing symptoms and (2) to prepare optimum soil conditions which suggests healing by restoring or making whole. These mechanics "fix" things. But the enterprise also depends upon the mysteries of sunlight, rains, and wind. Out in the fields, then, are the gardeners—family members, friends, clergy, educators and sympathizers—who patiently till the soil and tolerate the unexpected drought or flood. High tech medicine gives way to self-help groups, plus family, group, and one-on-one therapies. Balance and maintenance are primary. Immediate goals are accommodated to occasional setbacks in the effort to cultivate growth in the long term. Here science will not scorn traditional emphases upon individual uniqueness, needs, and responsibility. Qigong is learned and practiced by some, and tai

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jing exercised by others. Harvest time does not require cure; it celebrates "new life" on a plane now protected from the edges of chaos and despair.

Ultimately every farmer harbors hope. Combined with mutual respect between mechanic and gardener, hope also requires communication between the two. Lack of dialogue in cultivating the growing crop, in this researcher's opinion, is the greatest weakness in the western mechanic's treatment; by the same token, ignorance of biologically-based diagnosis and medications to confront weeds and parasites reduce the gardener's effectiveness. By complementing strength for each others' weakness, people capable of "having" and "holding" (the *root* meaning of the term "rehabilitation") will shape both harvest and reward.

❖ *Exploring the Severity of Post Traumatic Stress Disorder and Learning More Efficient Ways of Treating Chronic Trauma in the Gaza Strip and the United States*

John W. Raasoch, MD, Medical Director, Monadnock Family Services
Christine L. Sedor, MA, and Bryant Jordan, Correspondent, Manchester Union Leader

During October and November of 1992, Dr. John W. Raasoch, Christine L. Sedor and Bryant Jordan went back to the Gaza Strip. Their focus was on the refugee camps and especially the children. This study built relationships with Gaza Community Mental Health Program and completed a research project begun last spring and set up a formal liaison with an exchange program.

Raasoch and Sedor studied severe trauma imposed by extreme oppression, political torture and the violence which results from such circumstances. They looked at similarities and differences between Gaza and America in the treatment of trauma-particularly identifying strategies to accelerate treatment for more efficiency in our treatment of trauma victims. Long term political oppression and violence has led to the breakdown of the familial structures and subsequently the breakdown of a culture in Gaza. Parallels to similar circumstances in the United States specifically in urban areas such as Los Angeles were a focus of the study. Part of what has happened in the Occupied Territories is attributed to racism which is not unlike what we have in the United States.

Here in the United States we are always looking for ways to abbreviate treatment with trauma victims rather than continuing with the current long term approach. The Gaza Community Mental Health Program has been successful in many instances of having dramatic treatment successes with brief interventions while reaching a larger base.

Joining Dr. John Raasoch and Chris Sedor, was Bryant Jordan, Business Editor of the Keene Sentinel. He has done previous work in Israel, Gaza, and the West Bank. His study included how the unseen wounds of war and occupation are or are not treated. His writing and photographs were seen in the Keene Sentinel and will also made available to all newspapers which subscribe to the Associated Press.

❖ *Psychiatric Treatment & Rehabilitation for Seriously Mentally Ill Persons in China*

Robert Paul Liberman, M.D., Professor of Psychiatry, UCLA School of Medicine

Robert P. Liberman, M.D., Professor of Psychiatry at the University of California, Los Angeles, School of Medicine and Director of the Clinical Research Center for Schizophrenia and Psychiatric Rehabilitation, toured various mental health facilities throughout China on a Fellowship from the International Exchange of Experts & Information in Rehabilitation of the World Rehabilitation Fund. During his travels, Dr. Liberman gave lectures, workshops, and seminars to mental health professionals, teaching them many of the behavioral techniques developed, evaluated and utilized at his clinical research center in Los Angeles, California. During his extensive visit to China, Dr. Liberman had the opportunity to observe the quantity and quality of mental health services in metropolitan and rural provinces within that country. The report of his experiences offer interesting observations and insights regarding the limitations of psychiatric practice as well as ideas and suggestions that may be adapted to help solve many of the rehabilitation problems experienced by clinicians in the US.

Treatment of the seriously mentally ill in China, consists of a variety of circumscribed, traditional and non-traditional therapies, centered around long term hospitalization in facilities very similar to immense state hospitals of the past, in the US. There are also a limited number of out-patient treatment centers such as day hospitals, vocational rehabilitation sites, and supervised or supported housing for the mentally ill; these are primarily located in the large cities in a country where the majority of the population live in rural provinces and depend on village or country doctors for their psychiatric as well as medical care.

Diagnosis of mental illness is made using criteria similar to those mandated by the DSM III-R, and while the Chinese have access to and utilize the same or similar psychotropic medications to those we use to control the worst of psychotic symptoms, their overall treatment philosophy is very different from ours. Yet in their clinicians, there is strong desire and eagerness to join the western world, particularly the US, in utilization of the newest therapeutic technologies. ***Continued on next page***

To this end, the Chinese government is importing expert mental health professionals from all over the world to introduce, teach, and advance ideas for rapid modernization of psychiatric treatment, including the concept of patients' rights for the hospitalized mentally ill. This growing desire to "Open China to the West" as postulated by the Communist Party's Five Year Plan, gives western countries the opportunity to explore an entity in China known as the "work unit", and in particular, its relationship to and impact on psychiatric treatment and especially on the recovery of people who are seriously mentally ill. The "Work Unit" is fundamental to individuals' identities in China since the majority of working citizens begin and end their working lives in a unit, whether it be a factory, farm, commune, office, hospital, or school. As part of its total control over the workers' lives, the Chinese work unit is able to incorporate work as a modality for social recovery of the seriously mentally ill.

Life-long assignments to work units not only provide workers with their livelihood, but entitle them to have the work unit assume responsibility for locating and funding in-patient and out-patient psychiatric services. When the worker recovers enough to be released from the hospital, the Work Unit is also responsible for providing some form of productive work within the unit, for the newly discharged, disabled worker.

Lieberman observed that the Chinese system of locating financial responsibility for psychiatric services in production-oriented work units contains the seeds of more effective supported employment program mechanisms than are currently available in the US. This fiduciary responsibility for psychiatric services held by factories, offices, companies, etc. in China, seem to indicate the possibility of a smoother transition from hospital to community based care for them than for the US where funding is rigidly controlled by the state and federal bureaucrats, who have shown a great reluctance in the past to turn over funding control to local authorities.

The Chinese share many problems and obstacles with the Western World in the treatment and rehabilitation of seriously mentally ill persons. Some of these include housing, special burdens experienced by families who are expected to take care of their mentally ill loved ones, and consumers continuing to suffer the stigma of mental illness. Clinicians neither in the West nor the East have clear answers to these and other problems, therefore, their resolutions are areas for strong, ongoing collaborations, with each examining their respective cultures for clues to success that when adapted, exceed the expectation of either.

❖ *The Changing Mental Health System in New Zealand*

Fran Sylvestri, Executive Director, Monadnock Family Services, Keene, NH

Excerpts From His Report

In the United States, the National Alliance of the Mentally Ill conducted reviews of mental health delivery systems throughout the country. Their last report, published in the fall of 1990 identified only seven states that they felt offered the basic services to support Americans with long-term mental illnesses. They further identified the weaknesses of each state, not only in the other forty-three states and District of Columbia, but also areas that needed improvement in the seven which met their minimum standards.

The State of New Hampshire was one of the seven states that fortunately passed the test of the Alliance. But our pride was tempered with the list of areas that needed improvement, and the day-to-day struggle we face to keep our services functioning in light of dwindling resources and very high federal deficits.

Since 1976, our center's philosophy has been to look outward to other service providers within the U.S. and outside the country. We feel there is very little *practical* research being conducted in the *design* of mental health systems. In order for our small center to succeed, we need to look beyond our borders. *What we need are practical solutions.*

As part of our center's sabbatical leave program, I chose to visit New Zealand and applied to IEEIR for a fellowship to study how New Zealand was delivering services to the long-term mentally ill. I chose this country for several important reasons. First, and primary is that New Zealand, while having conducted deinstitutionalization in the past ten years, was now in a state of transitioning services from institutional control to local control. The country and its Area Health Boards were given mandates by their government to improve community services and to transfer to the community the more difficult consumers who were needlessly residing in public hospitals.

The second reason was that New Zealand shared similarities to New England, especially with the northern three states of Maine, Vermont and New Hampshire. We have similar populations, have large rural areas and have long historical ties to English traditions.

Third, there is a rich local independent attitude that translates somewhat to expectations of being self-reliant. Consumers in New Zealand and in northern New England share some of the same cultural heritage.

Finally, New Zealand has a large Maori population, and thus would offer the chance to see how western theories of mental health are viewed through a different perspective. It would challenge how I look to solve certain delivery needs.

I was especially interested in housing and vocational programs and how these services integrated the case management needs of their consumers. There is discussion presently taking place in New Zealand as to which service is a higher priority, housing or case management, and when to initiate vocational services.

Another interesting element is the strong consumer movement of psychiatric survivors and how they have influenced the system of care in New Zealand. ***Continued on next page***

Mental Health Policies in New Zealand

While deinstitutionalization has occurred in New Zealand during the past ten years, the national government did not have a clear and concise policy that encouraged a more organized and effective shift to community services. In a series of studies beginning in 1988 under the Labour Government, national reports have been completed that discuss the need to shift both resources and consumers from institutional settings into local, community-based settings.

Report of the Mental Health Consortium

The ministers of Health and Social Welfare requested that the Cabinet's Special Equity Committee establish a Mental Health Consortium to find solutions to the problems in establishing community programs for long-term mental health consumers. The following was the charge given to the 32-member committee:

1) Establish national policy objectives and priorities within the statutory sector for the development of community mental health services. 2) Report on the respective roles and responsibilities of statutory agencies and how these interface with each other and with private/voluntary sector service providers. 3) Identify the resources currently available for people with psychiatric disabilities and the extent to which these resources can be utilized to achieve the development of comprehensive community support services. 4) Recommend ways of promoting greater accountability for performance in respect to the roles and responsibilities outlined above. 5) Recommend ways of promoting greater coordination of statutory and community agencies to facilitate the development of community mental health services at the local and regional levels, in line with any broad national policy objectives. 6) Establish criteria for the allocation of community mental health service development funds, including cultural sensitivity in services, and approve the distribution of funds accordingly.

Cost Effectiveness Versus Cost Efficiency

As community care proceeds, it is common to find that politicians on both sides, liberals and conservatives, agree that community mental health care is an appropriate alternative to hospitalization. This unique alliance is due to the fact that liberals see community health services as cost-effective, and provide better care to the mentally ill. Conservatives see community service as cost-efficient, or the cheapest alternative to costly institutionalization.

Community mental health care has a unique advantage in that in can prove that it is a more effective, better method of caring for consumers, while the lower cost of care and efficient use of tax dollars can be documented....Therefore, in areas of the United States and in other parts of the world, arguments should be reframed for the audience who currently has the authority to improve community care. But the message of effectiveness is important to convey even to those who are interested primarily in cost efficiency.

I found this true in New Zealand, as I did in Italy in 1983, as well as in my experience in New Hampshire. What we can learn from this is that rather than worry during a change in government, providers, advocates and consumers need to reform their arguments and supporting data. Community mental health care has a unique advantage in that it can prove that it is a more effective, better method of caring for consumers, while the lower cost of care and efficient use of tax dollars can be documented.

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Housing Corporation

During the past three to four years, New Zealand's Housing Corporation had a dramatic effect on the delivery of services and the support provided to consumers leaving the institutions. While the Housing Corporation has not had a uniform effect on the entire country, many areas have used flexible housing benefits to add excellent units to the pool of flats available to the consumers.

The Housing Corporation has offered two special services in their Community Housing Program, special tenancy and special lending. These services allowed area health boards or trusts to place consumers into supplemental housing units that were either owned by the Housing Corporation (special tenancy), or were purchased by the trust or area health board through special lending.

The special lending service is an extremely reasonable financing arrangement that requires the purchasing agent to provide either a low down payment (5%) or none at all, and then a low interest rate.

Any trust would identify a consumer's need and request that the Housing Corporation obtain a unit. The corporation would, if necessary, acquire a house or flat for the trust. If the trust located a property and wished to own it, the Housing Corporation would provide the financing.

Unfortunately, changes have taken place that eliminate the Housing Corporation. Due to New Zealand's financial budget deficit, the government decided to take stock of the housing units the Corporation owns and move the rental rates to market rental rates.

Rakou Ora Trust

There is a debate in the mental health field in New Zealand concerning which of the two services, housing or case management, should take priority if funding is restricted. Even though

Continued on next page

both are essential, many public mental health systems have to make a choice between the two in their first investment forming a community support network.

The Geography Department of the University of Auckland has been researching the effect of the quality and location of housing for the consumers who have been discharged from public institutions. They mapped the location of most of the consumers through the city. The early results revealed that the location of consumers substantiates what most mental health systems experience - that consumers are generally restricted to lower income and often substandard housing. This is due both to the lack of resources and a general bias on the part of landlords in better quality neighborhoods.

The Geography Department attempted to compare those consumers within substandard neighborhoods and those in better quality locations, and found that readmission rates to institutions were no different. The early conclusions presented by Dr. Robin Kearns at the first National Forum on Consumer Centered Community Housing held in November 1991, was that housing was important, but not as important as the role of the social network. This network includes both consumer and professional supports.

One could conclude that case management is therefore, more important than housing. Or one could surmise that substandard housing is tolerated more by consumers because of low expectations.

Framework Trust

Framework Trust is a successful attempt in providing both pre-vocational and vocational services to consumers. Framework is a non-profit charitable trust that was organized in 1985. It is managed by a Board of Trustees that represent providers and other professionals in Auckland. Consumers are invited to all Trustee meetings, and the Trust surveys the consumers on all new projects.

They provide service to all districts within the Auckland Area Health Board, and services can be grouped into four categories:

- Social/Recreation
- Pre-vocational skills development
- Vocational Services
- Housing.

The atmosphere within the centers is similar to the feel of the Italian worker-owned cooperative and our own Wyman Way Cooperative in Keene. Products or activities are vocational in nature. Consumers who attend see it as a work site, and develop basic employment skills.

Framework also has initiated some small industries, with the idea of their becoming independent profit centers. These groups, such as the organic gardeners and the proposed paper recycling business, are moving toward the cooperative effort.

Framework Trust sees itself as a business that can assist and create other small businesses for consumers. Consumers with whom I spoke felt very positive and empowered by the Trust's work and the leadership of the staff.

Housing is a new component that was in its early stages during my visit. The Trust was building three buildings behind its main office that will offer five rental apartments and an apartment for a support person.

A unique aspect of Framework is that they are attempting to isolate the various elements of social/recreation, pre-vocational and vocational by separating the facilities. I feel that charitable trust's model for organizing the Trust is an appropriate one.

Several issues that Framework Trust is facing are the following:

- The role of consumers, as they become more of the backbone of several enterprises, may have to be incorporated into the management structure. Consumers will begin to want to share in the authority and operation of the business they work in.
- Consumer training in the art of management and supervision will need to be initiated. This is a vocational need as consumers become more successful in their careers.

An interesting concept is what happens to a cooperative that becomes successful and profitable. Does it become fully independent, or does it continue some relationship with Framework Trust?

The trust is a model that may be very useful to U.S. urban centers, where there is more than one community mental health care center or provider of services to the long-term mentally ill. Having one trust, with the responsibility to assist in the development of a cooperative, could afford a more rapid initiation of a cooperative.

I found many of the basic beliefs that I experienced and understood in the Italian Work Cooperative and Wyman Way Cooperative existed in Framework Trust, as well. The trust sees its role as assisting individuals to gain a sense of self-esteem and confidence in a warm and supportive environment. The trust respects individuals and their unique needs and operates to provide an opportunity to acquire skills to work and, ultimately, a job, at whatever level a consumer can work.

❖ Attitudes and Cultural Biases

❖ Social Preferences of Maori Children Towards Visible Physical Impairments

Dennis C. Harper, Ph.D., University of Iowa, Department of Pediatrics

Dr. Dennis Harper,) at the University of Iowa, has been conducting research on children's attitudes toward physical disability in Western and non-Western cultures since 1983. He was awarded an IEEIR Fellowship and a Visiting Professorship to the Department of Psychology at Massey University in Palmerstown North, New Zealand, in March - April 1993.

This research focusing on children's attitudes towards visible physical disabilities has been part of an ongoing research program exploring Western (U.S.) and non-Western views of physical disability. The research has emphasized the point that examination only of Western cultures may promote the mistake of attributing stigmas of particular handicaps to uniquely Western influence. The understanding of our own cultural biases and stereotypes toward disabilities in the United States is more clearly understood by stepping outside our own culture and beginning to study disabilities and handicaps comparatively and collaboratively. The premise for this study is based upon several investigations completed in the United States, Nepal, Antiqua, and a project just completed by Drs. Sanchez and Harper in the Yucatan, Mexico. These studies have been completed in collaboration with local professionals in each country and have interviewed approximately 955 children. Such cross-cultural comparisons have assisted in developing useful strategies for teaching about handicap and assist in developing a broader world view toward children with physical disabilities.

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The specific purpose of the IEEIR study was to explore the attitudes of the indigenous Maori residents toward selected physical disabilities. The picture-based interview technique was used as it has been in previous studies through-out the world. The project was collaboratively developed with Dr. Robert Gregory, a Senior Lecturer in Psychology at Massey University in Palmerstown North, New Zealand. Local professionals (Mason Durie) and educators (Deanne Thomas) also collaborated and were the key to developing a project that was both ethically and culturally sensitive. The Maori people are experiencing many social and political changes in New Zealand at present. Investigators unfamiliar to New Zealand and the rich history and tradition of the Maori cannot easily obtain access to these study issues without both collaborators and much pre-planning time. Study visits require knowledgeable hosts, considerable preplanning time, and the basic requirement to be flexible in redesigning collaborative studies upon arriving in the host country.

The study required the employment of local interviewers conversant in Maori language and tradition. Such involvement provided invaluable assistance in developing and refining the interviewing protocols and obtaining the maximum benefit from the interviews of the Maori children. One of the interviewers, an advanced psychology student at Massey University, has continued and extended this work as part of an Honors Thesis. The project has been focused on interviewing Maori children living in more rural areas on North Island, New Zealand.

During the study-visit, approximately 135 children were interviewed and approximately another 60 children will be interviewed by June 1993. This level of outcome is possible only because of the close collaboration and mutual development of research objectives. The results of the study will be analyzed shortly.

The present study provided a unique insight into Maori children's attitudes toward their peers with physical disabilities at a time of much social, political, and economic change in New Zealand. The opportunities for collaborative interchange have left an indelible mark on my professional and personal attitudes toward child-based rehabilitation. Since disability awareness, its meaning and its impact clearly varies from culture to culture, firsthand collaborative studies are instrumental in understanding these fundamental issues.

❖ *Daily Life Experiences of Japanese Adults with Disabilities: An Exploratory Study*

Barbara Wilhite, Ed.D., CTRS, University of Georgia

The purpose of the was to understand the daily life experiences of a sample of Japanese adults with disabilities. Answers to four primary research questions were sought: What are the typical daily life experiences of adults with disabilities? How are daily life experiences influenced by disabilities? What formal and informal supports are typically utilized? How satisfied are individuals with their daily life experiences?

The domain of daily life is one in which adults may create interdependence, achieve productivity, and experience integration. Specific activities, locations, and interactions of daily life are influenced by national structure, values, beliefs, and by policies and attitudes concerning people with disabilities. Individual characteristics and constraints influence opportunities and choices in daily life. And personal meaning is mediated, if not determined, by cultural conditions.

Cultural knowledge is important in understanding disability-related issues. Individuals without disabilities, or living in another culture, cannot fully know or appreciate these influences. A comparison of Japanese and Western social structure is useful in understanding attitudes towards individuals with disabilities in Japanese society. The significance of independence and individual identity i Western society is in contrast to the Japanese emphasis on group decisions and conformity. Tremendous variation exists among individuals i any society, however, and it is important to consider this variation. Therefore, it was necessary to seek out and listen to the voices of Japanese with disabilities; to learn about their experiences and the meaning they attached to them within their cultural context.

In-depth, focused interviews were conducted with a purposive sample of Japanese adults with disabilities. A medical doctor served as key facilitator in Wilhite's study. He helped to recruit respondents, arranged for interviews and provided translation. He contributed corroboratory evidence, shared insights, and suggested possible interpretations of responses. Other Japanese informants helped to confirm insights and provided additional evidence for drawing conclusions.

Thirteen respondents, ranging in age from 20-72, were interviewed. Their disabilities included such things as spinal cord injury, polio, amputation, and arthritis. Self-perceived health status ranged from excellent to poor. Six of the respondents worked full- or part-time. Others were housewives, retired or unemployed.

Most respondents kept an active, routinized daily schedule. Each respondent received formal and/or informal assistance. Perceptions regarding the adequacy of this assistance varied. Respondents were generally satisfied with daily life and expressed enjoyment gained from simple pleasures. Respondents reported that perceived or real limits imposed by their disability contributed to feelings of boredom, loneliness, and ostracism.

Major themes emerging from the data included consistency in daily life, dependency, belonging, and marginality. Consistency in daily life provided respondents with a sense of security and control, yet did not insure personal choice or freedom. It often represented imposed restrictions or limits. Respondents were dependent, to varying degrees, on assistance form the family, friends, the community, and the government. A desire for more independence was strongly voiced. Dependency without reciprocity diminished respondent's freedom to voice their opinions. The importance of belonging and the fear of ostracism or social disapproval emerged as a prominent theme. Loneliness expressed by some respondents was a result of their anxiety about "being left out." Belonging was afforded through employment, affiliation, with the social welfare centers, and through meetings and social events involving people with disabilities. No other factor seemed to negatively influence the daily lives of respondents more than their perception of marginality, not completely an outsider, but not completely accepted.Findings pointed to possible similarities and differences in the experiences of Japanese and Americans with disabilities. Japanese respondents were more concerned that the researcher understood the essence of their daily lives, however, and did not appear compelled to illustrate similarities or differences with others. It was apparent that the respondents wanted to talk about their individual situations; that they appreciated an audience, someone to listen. Respondents were thoughtful, reflective, and candid during the interview. They spoke with confidence, animation, and sincerity. At times respondents were quite serious, and at other times, they smiled and laughed easily.

Barbara Wilhite's Postscript:

During my first study visit to Japan, I felt very much like the outsider that I was. The key informant warned me that respondents may not answer all questions, especially the ones he considered "personal". In my initial conclusions I stressed the difficulty of freeing oneself from individual and cultural influences, and interpreting the Japanese way.

In August 1993 I returned to Japan and interviewed 11 of the 13 people with disabilities I had interviewed before. The opportunity to conduct follow-up interviews clarified and confirmed initial conclusions, and provided further insight into the daily lives of these individuals. Respondents told me that they were initially hesitant to answer my questions . "We had never been asked such questions before." They felt I was genuine, however, and thus spoke openly. To my surprise, the respondents stated that had I been Japanese, they would not have felt as free to share their thoughts and feelings. "It is not within our culture to pay attention to ourselves." Because they perceived me as sincere, *and* because I was "not within their culture," they responded candidly.

As I reconsider the theme of marginality, we shared more in common that originally felt. In this sense, "being an outsider" had advantages. The personal and professional value of conducting follow-up studies was clear.

❖ Developmental Disabilities

❖ The Effects of Privatization on the Delivery of Mental Health Services in Israel

Marvin S. Kivitz, Ph.D., International Association of Jewish Vocational Services, Philadelphia

Much of the notoriety in the field of mental retardation in the United States over the past twenty years involved State operated facilities such as Pennhurst, Willow Brook, Partlow, etc., where the state was the monitoring agency as well as the provider of direct care. Since 1980, Israel has been conducting an exciting experiment in privatization of State operated mental retardation facilities and services. A study of those activities was conducted to evaluate the effectiveness of transferring responsibilities from state to private non-profit organizations. Structured interviews were conducted with governmental officials, providers of services, recipients of the service and their families and advocacy groups such as AKIM (The Association for Retarded Citizens), in order to gain an understanding of perceived need for change, the process that was undertaken to bring about privatization, the obstacles that had to be overcome to transfer responsibility for the state to private providers, the effects of the changes in quality and comprehensiveness of service, the advantages and disadvantages of the two systems, etc.

The respondents unanimously reported that they felt that privatization was a process that was necessary and desirable. Almost all felt that privatization was just beginning and would be greatly expanded in the future. Most respondents felt that the private non-profit agencies in the future would provide most of the services for mentally retarded persons. All felt that the government should stop providing direct care; however, the government should be responsible for funding services and assuring the adequacy of such services. A few felt that the government should continue to be involved in the provision of direct care to the extent that they could provide emergency care and services for those individuals "unacceptable" to private agencies. Most people contended that a strong system of advocacy was required.

Almost unanimously it was felt that the private providers offered a better quality of service, had an easier time initiating new programs and establishing new services. Almost all felt that the private non-profit agencies were most cost effective but not necessarily the cheapest. There were some respondents who felt that state operated or private for profit agencies might be cheaper because of minimal or reduced services to the client and the family. The statement that "private non-profit agencies are not necessarily (or should not be that much cheaper) but should use funds to provide a better quality of service" reflects the most consistent attitude. The most consistent belief expressed in the interviews was that privatization of human services in Israel should and will be pursued with vigor.

Respondents envisioned and recommended a system of services where quality of comprehensive care would be assured and funded by the government; based on standards established by the government in consort with professionals, providers of service, consumers and advocates; where the services would be provided by private non-profit or for profit agencies; licensed and inspected by the government; where advocacy groups would continually seek strong national and local policies to make certain all clients and families were served and that the system was functioning appropriately.

Since the privatization process began with services for individuals with mental retardation, privatization has occurred in facilities serving the elderly, mentally handicapped, juvenile offenders and in other human service agencies. Since the publication of this report, other American agencies have become involved in providing private services in Israel or are in the process of exploring the possibilities. Results of this study have implications for public policy and planning in the United States as well as countries of Eastern Europe and the former Russian republics that are moving from a socialist system toward social systems involving privatization philosophies.

❖ Services for Disabled Children and Youth: Special Reference to Developmental Disabilities

Helen M. Wallace, MD, MPH, San Diego State University, San Diego, California

Helen M. Wallace, MD, MPH had a study-visit to India inNovember-December 1991 to observe and consult on services fordisabled children and youth, with special reference to the mentally retarded. My counterpart was Professor Prema Bali, Professor of Community Medicine, All India Institute of Medical Sciences, New Delhi. Professor Bali and her husband, a prominent architect, were the parents of a 23-year old daughter with mongolism. Professor Bali was the first President of the Parents Association (Association For The Welfare of Mentally Handicapped Children).

Overview of Visit

During the time in India, the following types of activities occurred:

1. Visits to observe programs for the mentally retarded schools vocational services school and educational/training program in Hyderabad
2. Conference with members of the Board of Directors of the Parents Association (Association For The Welfare of Mentally Handicapped Children)
3. Appearance on a public radio program
4. Attendance at a public meeting of the Parents Association
5. visit to a rural area near New Delhi as the site of a possible pilot community-based program for disabled children and their families
6. Development of the plan for the pilot community based program for disabled children and their families
7. Conferences with representatives of major agencies-i.e. UNICEF in New Delhi Ministry of Social Welfare in New Delhi

program for disabled children and their families
7. Conferences with representatives of major agencies-i.e., UNICEF Ministry of Social Welfare in New Delhi

Subsequent Follow-up Activities

Following the study visit to New Delhi, Professor Wallace has been engaged in two types of follow-up activities:

1. Arrangements for Professor Bali to present papers at the Annual Meeting of the American Public Health Association in Washington, DC (1992 and 1993) and of the American School Health Association (1992)

2. Extensive efforts to raise funds in the USA for the pilot program in India. At the same time, Professor Bali has been active in efforts to raise funds in India to support the pilot project. Professor Bali will also make a presentation at the Annual Meeting of the APHA in San Francisco in October 1993.

Unfinished Business

1. To raise funds to support the development of the pilot project in India
2. To raise funds for a 3-month study tour for Professor Bali to visit and study the spectrum of services for disabled children, youth, and their families in one or more communities of the US.

❖ *Creating Desirable Futures in the U.S. and Australia*

Jeffery Strulley, Executive Director, Jay Nolan Community Services, Valencia, CA

My wife and I are parents of three young people with developmental disabilities. We have worked for the past thirteen years developing fully inclusive communities that try and celebrate diversity by welcoming our children into the fabric of community life. This has included full inclusion in our schools, a strong circle of friends, integrated paid employment and living in your own home with appropriate supports. It means having a desirable future filled with rich and exciting experiences.

In May, 1992 I was provided an IEEIR fellowship to travel to Australia and meet with families throughout New South Wales and Queensland. During my five week visit, I had the opportunity to meet hundreds of families who were struggling to find the supports that they needed in order to have their children have a decent life in the community. I stayed with families for most of my visit listening to their stories and hearing them voice their concerns, feelings, and frustrations. They were concerned about the lack of resources and lack of integrated opportunities. They were worried about the future for their children.

The bottom line is what do families do when things are not working for their son or daughter? How do they deal with the discrepancy between what they want for their children and what is provided? How do you live with that tension?

I went to Australia to learn what families were hoping for. I came away with an understanding that the struggles and experiences for families in Australia as well as in the United States are very similar. I learned that families felt disempowered and angry with the way the human service system has or has not met their needs. I learned that families wanted more than what was happening for their children. Families wanted the good life for their children, but governmental policies, funding, regulations, and human service decisions did not support these dreams in many cases.

Families who had children with more significant challenges were less likely to receive what they needed as compared to people with less challenging needs. The similarity between families in both countries was remarkable. What policy makers and human service managers told families and their experiences were very, very similar. Though there were lots of similarities, there were also differences.

What was different was the role that culture played in the lives of the families. Families in the United States, for the most part, are willing to take individual action to impact change. This does not mean that all families in the States are willing to take on the system either legally, politically or otherwise. However, there are many examples in the United States where families have stood up and said NO! I want something better for my child. This behavior does not seem to exist in Australia. In Australia, individual action is not viewed as an acceptable means to make positive change. There is a need for collective action which will help lots of people. Many families in Australia could not relate to the individualism that exists within the United States to cause positive change. This difference is significant in many ways. The bottom line is what do families do when things are not working for their son or daughter? How do they deal with the discrepancy between what they want for their children and what is provided? How do you live with that tension?

The quality of services in the United States and Australia is similar. For the most part, segregated programs are the prevalent model in both of our countries. However, there were isolated pockets of excellent integrated opportunities in Australia. Though these pockets, for the most part, did not accept people with high support needs they were headed in the "right direction" for folks with lower support needs. In the States the same is basically true, however there are more places where people with very high support needs are being fully included than what was seen in Australia.

The real lesson that was learned, at least from what I can tell, is that families want the same stuff for their children. They want a better life and they are frustrated that their children are not receiving what is needed for a good life. How to make this change may differ, but the desire for something better is very similar. Families from both countries do want a desirable future for their children. What it looks like and how to get it differs. Families have dreams about a better future and a more inclusive community. The role of human service managers and workers is to stand with families to make this happen. Both of our countries should learn to listen to what families and people with disabilities want and desire a little more.

An Interim Report, Continued, from page 5

"The Illawarra Regional Health Service is divided into a number of facilities including local hospitals and community programs. To date, I have visited several sites. The main inpatient and outpatient rehabilitation units are housed at The Port Kembla Hospital located in the town of Warrangong. This is where I have traveled most mornings and have spent the majority of my time thus far.

My first week was devoted entirely to the hospital community and familiarizing myself with the rehabilitation program. I have attended case and family conferences, had meetings with psychologists and other staff members, participated in walk rounds with attending physicians and attended all team meetings. After attending walk rounds, physicians have often asked me my opinion of various cases. On the second day after my arrival, I served as a guest discussant when the rehabilitation team presented a difficult case of a young man with chronic pain.

Meeting with people with disabilities here in Australia has helped me to realize the similarities among people regardless of race and culture. As in the United States, each were struggling with the sudden changes in life style and dealing with the grief that often accompanies the onset of traumatic disability.

In addition, I have sat in on the individual and group psychotherapy sessions conducted by the staff psychologists and had ample time to discuss cases with the therapists after each session. Probably the most exciting part of my first week was the hours that I have personally spent with disabled patients doing individual and couples therapy on the rehabilitation unit. This rare opportunity has given me the chance to interview patients about *life with a disability in Australia* and to better understand the adjustment process that they have undergone in the months since their injury. In total, I have interviewed over a dozen patients during my first week as well as several family members who have significant others in the unit.

"Meeting with people with disabilities here in Australia has helped me to realize the similarities among people regardless of race and culture. As in the United States, each were struggling with the sudden changes in life style and dealing with the grief that often accompanies the onset of traumatic disability. It amazed me that people who are half a world away would be struggling with issues of dependence, marital role changes, being a burden and abandonment by friends and family. It has been one of the main inspirations of my trip thus far.

"Using my clinical skills in Australia, and earlier this year in India, has also greatly added to my self-confidence and positive feelings of self-worth as a therapist. I have been pleased that I have been able to develop a therapeutic alliance with patients and that patients have perceived me as being empathic, sincere and caring. This validation of my clinical work will certainly carry over to work back home and will strengthen my teaching and professional work.

"During the second week of my fellowship, the emphasis has changed considerably. Instead of observing the rehabilitation process, it is now my turn to give back and to provide staff education. Monday morning began with me attending the Illawarra Regional Health service psychology staff meeting. There, I presented a three hour workshop, to the nine staff psychologists, on the role of rehabilitation psychologist in the United States. Interestingly enough, there was great interest in the national health insurance issue in America. Australian psychologists were very concerned how managed care and case management systems were affecting the practice of rehabilitation psychologists in the United States. Monday afternoon, I traveled to the University of Wollongong, one of the joint sponsors of my study-visit, where I delivered two lectures. One, on spinal cord injury was given to the Department of Psychology, while the second, focused on epidemiological issues was given to the School of Public Health.

"On Tuesday, I presented at the hospital's grand rounds on the topic of spinal cord injury. I also attended another case conference and again served as a discussant on a case presentation. The remainder of my week was spent visiting community agencies and independent living programs in the area. I have visited The Headway Program, for people with head injuries, The Disabled Peoples Housing Trust, an independent living program as well as the Australian Quadriplegic Association which serves as an advocacy and peer counseling program for the spinal cord injured people of this area. Also, I have spent time at the "Paraquad" House, Department of Community Services and visited several group homes. In addition, I have visited a number of smaller hospitals who have community outreach programs. These have included the Berry Hospital, Port Kembla Hospital and the Kiama Hospital. Also, I have provided a consultation on psychiatric rehabilitation at the Wollongong Psychotherapy Center which had heard that I was in the area.

"As this week concludes, I will move my "base of operations" to the Sydney area where approximately two weeks has been organized. I will be visiting the two dedicated spinal cord injury centers in Sydney, spending a day at each. In addition, I will be visiting the independent living programs in Sydney with further hopes of understanding how they interact with the Sydney medical community. On Thursday April 8, 1993, I will be presenting grand rounds on Sexuality and Disability at the Royal Sydney Rehabilitation Hospital.

"At this point, I will conclude my interim report and will be sending in my final report within 60 days of my return. Needless to say, my study visit thus far has been a wonderful and enriching experience. This opportunity, has given me a new vitality and energy for my work and I look forward to communicating my experience to my students and colleagues back in the United States..."

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❖ *Developing Mutual Understanding Between Western and Non-Western Cultures Through Collaborative Research*

Judy Kuglemass & Kusdwiartri Setiono

During the summer of 1989, through the support of a fellowship from the World Rehabilitation Fund, Dr. Judy Kugelmass investigated the relationship that exists between culture and family adaptation to disability in Bandung, Indonesia. Through in-depth interviews of fourteen families with children identified as "mentally handicapped" and participant observation in their homes, schools, and communities, this project hoped to inform rehabilitation practitioners about the significance of cultural considerations when working with children and families in the United States.

As is often the case in qualitative/ethnographic research, particularly when an investigator enters a society quite different from her own, this researcher learned a good deal more than that which was anticipated. Of particular significance were the implications that emerged for applied researchers in rehabilitation or other human service endeavors in economically underdeveloped, non-western societies.

The findings of Dr. Kugelmass' report to the World Rehabilitation Fund focused on the existence of an indigenous system of caring that provided children with environments that maximized their functioning while providing support to their families. Although the formal educational and medical systems provided many services to the families interviewed, these were not perceived by parents as psychologically supportive. Instead, emotional as well as material support came primarily from extended family and local community networks and a belief system that focused on the importance of acceptance and patience that comes out of the religious beliefs and culture found in western Java. Although it was clear that the families interviewed were not representative of all Indonesian families or even of all families in Bandung that had children identified as " mentally handicapped," their ability to adapt successfully was seen as a function of their reliance on both formal and informal support systems.

These families did not, however recognize the significance of their religious and cultural traditions in their adaptations to their child. Parents and professionals consistently articulated their need for Western institutions and technology in order to more adequately meet the needs of their children. There was no apparent recognition that the most effective teaching and parenting strategies mirrored culturally appropriate interactions and the spiritual beliefs on which they were based. Dr. Kugelmass concluded that this lack of awareness was limiting opportunities for optimal and inexpensive treatment and education within the existing cultural context. The reliance on technological solutions to human problems that characterizes Western medicine and the looking towards the West for solutions by economically underdeveloped countries was pointed to as one source of this dilemma. The report advised American and Indonesian professionals to adopt an ecological framework in order to discover the strengths and sources of support that exist within their own societies, communities, and families when developing service plans for children with disabilities.

The dichotomy that exists in the attitudes many Indonesians hold towards Western versus traditional values and institutions must be considered when offering interpretations to applied research and in offering suggestions for service-delivery models.

Dr. Kusdwiartri Setiono, Professor of Developmental Psychology and Dean of the Faculty of Psychology at the Padjadjaran University was a primary collaborator for this project. Although both Dr. Kugelmass and Dr. Setiono met frequently in Indonesia, it was only through subsequent consultation and shared reflections in preparation for the presentation at the national conference of the "Society for Disability Studies" in Oakland, California in July, 1991 that both researchers came to a deeper understanding of the implications of these findings. Dr. Setiono was appreciative of the insights that Dr. Kugelmass' research offered into developing culturally appropriate and affordable special education and rehabilitation services in Indonesia. However, she felt that the conclusions of the research did not take other realities that exist in her country into account.

There was no disagreement that a philosophy of life basic to Indonesia is one of acceptance, demonstrated in the patience and warmth that characterizes the interactions between parents and children. Certainly, the social and emotional development of most children is enhanced through this kind of care. However, as Dr. Setiono pointed out, acceptance is not a wholly positive characteristic, either for Indonesian society or for children with disabilities. The religious origins of this philosophy are rooted in the belief that acceptance is a demonstration of faith that all reality comes from God and is to be faced with patience and understanding. It is also a belief system reinforced by the long colonial history of Indonesia.

Dr. Setiono believes that in order to achieve economic progress, Indonesians need to modify their belief system and become more active in shaping their own destiny. Similarly, acceptance can have a negative aspect when exaggerated by parents of children with or without disabilities. Examples of negative demonstrations of acceptance cited by Dr. Setiono and observed by Dr. Kugelmass in Indonesian parents of children with disabilities include giving the child whatever he or she wants; not limiting behavioral excesses; failing to systematically instruct the child in new behaviors or skills; not seeking outside, professional assistance.

Although the parents in Dr. Kugelmass' study represented a wide range of social class and educational backgrounds, none were

Continued on next page

from among the poorest in Indonesian society, and all had some degree of education. All the parents interviewed had sought help for their child from both "traditional," i.e., indigenous, and modern, i.e., Western based, services. Dr. Setiono believes that this demonstrated the importance of and possibility for modification of the philosophy of acceptance to include seeking help for your situation from those that exist around you. Such modification has come about through education and parents' understanding of the nature of disability. Among less educated people, particularly those in rural areas with limited access to outside information, the response to having a child with a disability is often quite different. Frequently, one of two extremes are seen: 1. The child is perceived as evidence of God's blessing and is responded to by treating the child as an honorable or saintly person. 2. The child's existence or disability is denied and he/she is kept hidden from extended family, friends, and neighbors, or unrealistic expectations/demands are placed on the child.

Another aspect of the research findings expanded upon through collaboration was the nature of the role of professionals in providing services to families with disabled children. Certainly there will never be enough doctors, psychologists, therapists, and teachers to meet all the needs of families in either Indonesia or the United States. Many Western countries are addressing this reality through a movement toward treatment teams that include para-professionals and parents. Self-help groups and the empowerment of "consumers" is another aspect of that movement. Although such an approach appears to be one that would meet many of the needs of a country such as Indonesia, the roles assigned to professionals and others in perceived positions of authority as well as the social class distinctions that currently exist present substantial barriers to providing services in this way. Although indigenous support systems exist at all levels of Indonesian society, unless there is a person or people in position of authority perceived as "in-charge" or "honorable," the information received and the advice given are not valued. Therefore, if a team approach or the use of informal systems are initiated, particularly in rural areas and among poorly educated people, a person with perceived authority must not only be in charge, but may need to offer the information directly to parents if it is to be perceived as true and therefore worthy of consideration. Although indigenous support systems exist at all levels of Indonesian society, unless there is a person or people in position of authority perceived as "in charge" or "honorable," the information received and the advice given are not valued.

Physicians and other rehabilitation professionals must therefore identify and collaborate with individuals perceived as holding positions of authority within traditional communities. Attempts at developing collaborations between physicians and "dukuns," i.e., the traditional healers that are respected and consulted by Indonesians from all levels of society, are being initiated. However, in spite of the fact that all Indonesians, including physicians, consult dukuns on personal health and spiritual matters, there appeared to be a resistance to public acknowledgement of this relationship among many of the professionals interviewed in Bandung. The resistance to open collaboration with dukuns can also be seen as reflecting the ambivalent attitude towards indigenous practices that comes from a colonial history. Although it seems paradoxical that a colonial past would limit Indonesians' willingness to become involved with traditional Indonesian practices, it is one of many examples of the love-hate relationship that exists between Western ideas and traditional Indonesian society. Although Western goods, services, and technologies represent the colonial past to some, they also offer the promise of technological and economic development.

The response to Western versus traditional ideas and practices varies throughout the country, and depends a good deal upon the ethnic history of the Indonesian people in question and their social class. Upper-class and professional Javanese and Sudanese people, as represented in Bandung, although proudly Indonesian and devotedly Islamic, have either been educated and trained in Europe, or received education and training in Indonesia based on a European model. Ethnic groups from other islands in the Indonesian archipelago are less connected culturally with the West, and so are less reluctant to identify themselves with non-Western traditions and institutions, such as the use of traditional medicine. These differences, and the dichotomy that exists in the attitudes many Indonesians hold towards Western versus traditional values and institutions must be considered when offering interpretations to applied research and in offering suggestions for service-delivery models.

In Conclusion

These expanded interpretations of the data from Dr. Kugelmass' study came about through the in-depth collaboration that occured between herself and Dr. Setiono. These modifications have certainly added to our understanding of what will be necessary in the development of services for children and families in Indonesia. Its significance also lies in the recognition of the importance of working collaboratively with a well-informed, local researcher such as Dr. Setiono, when conducting research in cultures other than one's own. This would be true between cultures as disparate as the United States and Indonesia, or within a sub-cultural group within one's own country. The collaborative relationship is more than the key informant/researcher relationship typically seen in ethnographic research. Rather, an ideal collaboration exists when two researchers interested in exploring similar issues work together, both bringing research and content area expertise to the work, each intimately familiar with her own culture, and knowledgeable enough of her partner's culture so that each is aware of the biases the other may bring. The collaboration should include research design and implementation, as well as the interpretations and implications of the results. Most importantly, the collaborative relationship must be characterized by trust and mutual respect for the perspectives of the other. The mutual understanding that results will benefit both the researchers and their respective societies.

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❖ *Life Span Housing in Japan* *Paul J. Grayson, M. Arch., AIA*

Environments for Living, Winchester, MA

Beyond providing an opportunity to evaluate the design effectiveness of Japan's housing program for people with disabilities and to maintain a continuing relationship with colleagues in Japan, my IEEIR fellowship was most instrumental in solidifying my research into the benefits of universal design.

Seeing examples of Japanese manufactured "life span" housing that is accessible and supportive of persons with disabilities in an inclusive from the start, not additive after the fact manner, was a revelation. It convinced me that on a macro scale, universally designed environments are both realizable and affordable for the US market. Ultimately, universal design is the most efficient way of approaching the problems of accessibility.

It is gratifying that such legislation as the Americans with Disabilities Act and the Fair Housing Amendments Act have been enacted providing the right climate for my personal mission of promoting the concept of universal design to benefit all.

James I. Charlton, continued from page 22

Many people with disabilities have long sought out the common experiences of each other to enhance their own ability to contribute to the successful organization and development of the community. This is especially true in places and countries in great flux where social change is happening on a grand scale, where empowerment and innovative strategies are necessary to survive.

Charlton makes two major observations. First, to understand anything about disability as a social strata or the disability rights movement (or any other movement or social strata for that matter), one must have some understanding of the political economy that group or movement is operating within . That is, what are the political, social/cultural and economic barriers to social progress. Secondly the disability rights movement is an anti-systemic movement that is confronting the realpolitik of Zimbabwe. That in some ways it is possibly the most influential and organized of these movements in Zimbabwe today. Charlton believes that the disability rights movement is one of many movements where new attitudes and world views are being created through their struggle and vision that require fundamental structural changes in everyday life.

The International Exchange of Experts and Information in Rehabilitaiton

❖ *Fifteen Years of an International Program*

Sponsored by the National Institute on Disability and Rehabilitation Research

- ***The Survey Questions***
- ***Fellowship Follow-up Survey Summary***
- ***Sample Responses to the Survey***

In this section the reader will find many of the responses to the survey questions. In order to organize the material, the sample responses to the survey questions are grouped under these headings: *Application Process, Impact on Professional Life, Outcomes and Benefits (to the field), Other IEEIR Benefits, International Networks* We have not included responses to all questions. We have included a substantial number of responses to several areas we felt would be of interest.

❖ The Questions

IEEIR Fellows' Follow-Up Survey (1993)

1. When and how did you hear about the IEEIR?

2. What inspired you to go through the process of completing an IEEIR application, and when did you do it?

3. Please indicate and comment on the extent the experience of the fellowship has influenced your professional life: quite a lot, in some major ways, somewhat, minimally or not at all.

4. Please explain how the experience of the fellowship has altered/influenced your professional life. (Please specify which areas: policy, curriculum development, program development, technology, practice, administration)

5. What would you say are the two most important outcomes of your IEEIR international visit?

6. Do you anticipate any future outcomes? If so, please describe.

7. Were there any major disappointments? If so, what were they? (Please take into consideration the fellowship itself and dissemination.)

8. Please comment on the overall benefits of overseas short-term visits.

9. What international experience had you had prior to the IEEIR Fellowship? Please indicate which apply: (1) travelling, (2) living abroad, (3) professional experience (hosting and/or visiting).

10. Please describe any international experience you have had after the IEEIR fellowship?

11. Have any of the IEEIR monographs, fellowship reports or other publications have useful to you in your career? Please explain briefly which ones and how you have used them?

12. How do you stay current on international advances in your field? Please indicate whether you are part of an informal network or formal network of experts in your field.

13. One of the uses of the IEEIR is thinking about making of this study is to make recommendations for a network of international resources for the mutual benefit of U.S. and foreign disability specialists. Some ideas include a loose-leaf directory of resources abroad and an electronic mail network. (a) In your view, would a formalized network be beneficial? To whom and how? (b) What role do you see yourself playing in an international network of experts in the disability field?

❖ IEEIR Fellowship Follow-up Survey Findings, 1978 to the Present: A Summary

Susan Frankel, Ph.D.

Introduction

During February, 1993, a survey was mailed to 135 International Exchange of Experts and Information in Rehabilitation (IEEIR) fellowship participants to assess outcomes of the program and to make recommendations for the future direction of the IEEIR program. Sixty participants responded to our 'follow-up' survey. Respondents covered the life span of the program, from 1978 to the present.

Findings

The findings are summarized in three sections: professional profile of participants, professional outcomes of experiences, and professional international resources.

Professional Profile of Participants

Table 1 summarizes key professional background information of the survey respondents. In terms of professional affiliation, 62% were associated with a university, 15% with a non-government organization, 8% with a hospital, and 7% with a state agency. Since so many of the respondents were associated with a university, it follows that nearly half of the sample mentioned education as the professional area in which they were involved. Other professional areas represented by the sample included 19% in administration, 15% in practice, and 20% in research or policy-making.

Fellowship participants heard about the program through a variety of means with friends and colleagues as the most frequently mentioned source. Fifty-eight percent of the respondents heard about the IEEIR program from friends and colleagues, and 29% knew about the program through publications. When asked what inspired them to complete the IEEIR application, 36% reported academic interest, and 15% said travelling abroad.

> I was very interested in seeing Conductive Education actually practiced in Asia and Australia.

> I was seeking international models to better understand how to develop home care for persons with severe physical disabilities in the United States.

> The idea was to see the influence of the environment and culture on the disabled.

Nearly all the participants had international experience prior to their fellowship. Sixty-three percent had professional experience (such as hosting foreign visitors or visiting), and 31% had travelled abroad. Eighty-six percent of the survey respondents had international experience after their fellowship visit. The types of international experience included conference presentations (28%), professional consultation (22%), general travel or as a host (20%), and further research (14%).

> I have been invited again by the Citizen Ambassador Program to lead a delegation about childhood disability, this time to Russia, Czechoslovakia and Hungry.

> Since the fellowship I have been a presenter at each of the International Congresses for Hard of Hearing, have travelled internationally and have hosted many foreign visitors.

Professional Outcomes of Fellowship Experience

The concepts I gleaned have been shared nationally. My horizons have expanded considerably. My agency is reaping the benefits through increased international recognition.

Table 2 summarizes the professional outcomes of the survey respondents. Sixty percent of the respondents indicated that the experience influenced their professional life somewhat. One third reported that the influence was considerable.

> In some major ways. The research has allowed me to take a better perspective of cultural variables in assessing what is often thought to be neuropsychological syndromes.

> The experience has had a major influence on my professional life.

When asked to comment on the extent of the experience of the fellowship, almost half of the respondents indicated that the experience had given them a broader perspective, 22% reported continued professional collaboration, and 29% indicated professional advance and/or expanded knowledge. Over 40% of the respondents reported that the major professional influence was in the practice of their profession, 22% reported changes in curriculum development, and 16% indicated program development changes.

> IEEIR has had a significant impact on my professional work in the areas of program development, policy and practice.

> The fellowship has led to a major and unique opportunity: to develop a program for and at the World Health Organization (WHO) in Geneva. The "Initiative of Support to People Disabled by Mental Illness" is now a part of the official program of work of the Division of Mental Health.

When asked about the most important consequences of the IEEIR visit, the following outcomes were mentioned: collaboration (60%), awareness of socio-cultural difference (38%), change in professional outlook (18%), and professional opportunities and advancement (30%).

> This professional experience led to the current position I hold.

> During this visit, I was also able to work with the host institutes to design tests for young hearing-impaired children, and to test six of the first young children with cochlear implants.

> The first important outcome is an ongoing interest and commitment to working in Latin America and an increased recognition of how much other services within the United States can benefit from openness to learning best practices from another area.

> My ability to see how good international program ideas can be adapted to different national funding systems and philosophies.

One of the unique features of the IEEIR fellowship is the short-term, intensive nature of the experience. When asked about the benefits of overseas short-term visits, 39% indicated general enrichment, 22% stated that the time frame was appropriate, and 13% expressed lasting contacts. Examples of 'Other' responses included:

> When well planned, and with a plan to integrate the experience with future endeavors, the benefit is great.

> In order to benefit from a short term visit to another culture, the visitor must either be familiar with the culture or be *very* focused in the questions he/she asks.

Professional International Resources

Table 3 summarizes information about international resources and the professional utilization of IEEIR publications. When asked how participants stay current on international advances in their field, publications (56%) were mentioned as the most frequent source, followed by professional memberships and affiliations (19%), contacts (17%), and meetings or conferences (4%). Over 50% of the survey participants stated that they were part of a professional network. When asked about the type of network in which they participated, 50% indicated that it was an informal network.

Over 80% of the respondents stated that IEEIR publications have been valuable in their career. Thirty-nine percent of the sample used the publications for reference, 26% for general interest, 23% used the materials in teaching, and 10% stated that they circulate IEEIR publications.

> I believe IEEIR monographs are pace-setting and have used them extensively in my teaching.

> Many IEEIR monographs provided background information and helped to structure my project in Israel. I also use the monographs to provide information concerning aging, employment, residential care, cultural diversity related to services for disabled individuals.

> As I review the fellowship report and monographs (not to mention my own experience), I am impressed with how significant the studies were in shaping rehabilitation policy and practice.

Conclusions and Recommendations

I have distributed my report at every opportunity, such as giving copies to physicians, teaching medical interns, giving presentations, workshops and seminars at professional meetings to educate professionals about what I have learned in the area of patient- doctor communication.

Conclusions

The primary conclusion of this Follow-Up Survey is that the IEEIR Fellowship experience has a profound effect for the recipients. These effects include overall expansion of professional experience and knowledge base. Based on the survey responses, it is clear that IEEIR fellowship provides opportunities to develop international connections and strengthen existing connections. As a result of these opportunities, many fellowship recipients have become professionally active in developing programs and creating policies in order to improve services to people with disabilities. Furthermore, the information gained is disseminated through various sources such as journal articles, course materials, training materials, at national and international conferences, and through collaborative research opportunities. In essence, the IEEIR fellowship program has been successful in fulfilling one of the program's primary goals: to enhance information and knowledge exchange in the field of rehabilitation through international experiences.

Recommendations

Two major suggestions for future directions are presented below:
1) Develop a network of international resources for the benefit of both U.S. and foreign disabilities specialists. Most of the survey respondents expressed interest in a collaborative network. The IEEIR program has the wonderful advantage of being established as an important resource for professionals in the rehabilitation field. The practicality and usefulness of an electronic network could be explored as one type of collaborative network.

2) Expand the fellowship experience to 'new' professionals in the field. The fellowship experience had proved to be a successful experience for professionals established in their fields. It would seem that the opportunity could also be influential in shaping the career of young professionals.

See next two pages for tables

TABLE 1
Professional Profile of Survey Respondents

Characterisitics	Percent of Respondents
Affiliation	
University	62
Hospital	08
Non-government organization	15
State agency	07
Other	08
Professional Area	
Education	47
Administration	19
Practice	15
Research	14
Policy-making	05
How Know About IEEIR	
Publications	29
Friends and colleagues	58
Meetings or conferences	06
Other	07
Motivation To Apply for Fellowship	
Academic interest	36
Work experience	14
Colleagues	14
Going abroad	15
Other	22
Prior International Experience	
Travelling abroad	30
Living abroad	03
Professional experience	63
None	03
International Experience After the Fellowship	
No	14
Yes	86
Type of International Experience	
Conference attender	04
Conference presenter	28
Professional capacity	22
Further research	14
Travel or host	20
Correspondence	12

TABLE 2
Professional Outcomes of Survey Respondents Characteristics
Percent of Respondents

Characteristics	Percent of Respondents
Extent Fellowship Influenced Professional Life	
Quite a lot	33
Somewhat	60
Minimally	07
Comments About Extent of Influence	
Broader perspective	46
Collaboration	22
Professional advance	12
Expanded knowledge	17
Other	03
How Fellowship Influenced Professional Life	
Practice	42
Curriculum development	22
Policy	14
Program development	16
Technology	02
Administration	02
None	02
Outcomes:	
Collaboration	60
Increased Awareness	38
Professional Outlook	18
Professional Opportunities	30

TABLE 3
Professional Resources of Survey Respondents

Characteristics	Percent of Respondents
How Stay Current on International Advances	
Publications	56
Meetings or conferences	04
Professional affiliations	19
Contacts	17
Other	04
Have IEEIR Publications Been Useful	
No	18
Yes	82
Use of IEEIR Publications	
Circulate	10
Reference	36
Teaching materials	23
General interest	26
Other	05

❖ Sample Responses to Survey

The Application Process

When and how did you hear about the IEEIR?

❖ "I read about the WRF international fellowships in the former *Rehabilitation Literature*." (H. Versluys, 1983)

What inspired you to go through the process of completing an IEEIR application, and when did you do it?

❖ "The Fellowship would give me the opportunity to carry-out a long-desired plan to learn about policies and programs in Western Europe. The application for the Fellowship required a sensible amount of time to complete." (S. Zimet, 1986)

❖ "I requested that some of the publications I had read about be sent to a woman I had worked with in the Ministry of Health in Kenya. IEEIR sent the publications to her and sent me a packet of materials about the organization including an application form. When I met the woman once more in Kenya in July, 1991, she was delighted with the materials she had read and suggested that I apply for a fellowship to work with her. We outlined the proposal together. Her supervisor gave verbal approval at that time and I followed through with the formal procedure after returning home. Since written approval from the supervisor was not obtained until quite late, I did not finish the application until near the deadline — Dec., 1991 or Jan., 1992."
(P. Ginsberg, 1992)

❖ "I was very interested in seeing Conductive Education actually practiced in Asia and Australia. A colleague of mine (Judy Ferren, an Educator) also applied for (and received) the IEEIR fellowship. We were eager to go as a team, because we know that it's important to have more than one person recommend changes in program delivery back at our home base. Neither of us could have afforded to go without the fellowship monies. We applied in February 1988." (M. Marx, 1988)

❖ "While teaching PLU students for Spring semester at Chengdu University of Science and Technology on an exchange program I saw persons with mental disabilities on city streets in Chengud, PRC. Conversations with a traditional physician, Wang Xiapoeng stimulated my courage to apply. Upon return to the USA I worked on the application during September and October 1991." (S. Govig, 1992)

❖ "The application was submitted in April 1991. I would NEVER have been able to travel to Australia to see their programs without this type of support. My agency could not have paid for it nor could I. I felt that being able to see these programs would be very valuable for me personally and professionally." (M. Bagley, 1991)

❖ "I was inspired to go through the process of the IEEIR because of my desire to do a study of the disabled in the villages in the region of Bangalore, India with a base at St. John's Medical College. It has an outstanding department of community medicine. I had visited St. John's in 1987. The idea of studying the disabled was to see the influence of the environment and culture on the handicapped. This was derived from the study of a whole village in France by colleagues and friends, namely Prof. Pierre Minaire and Jean Cherpin of Lyon, France. They showed that the environment had a major factor in determining the handicap." (E. Bleck, 1989)

❖ "I had spent a summer in Indonesia in 1988 on a *Fulbright* fellowship and began to develop research questions regarding childhood disability in that society. Indonesian colleagues expressed an interest in further collaborative work. I completed the application in 1988 - 1989." (J. Kugelmass, 1987)

❖ "A major catalyst for completing the application was the fact that Rud (my husband) and I had been invited to participate in a conference in Argentina and Brazil. We were invited by Eloisa de Lorenzo. We had been working with Eloisa and were extremely interested in aspects of the Latino culture, particularly related to issues of strong family solidarity and the definition of independence within the family system. Thus, it seemed to be a good opportunity to go to Latin American countries to learn about their experiences and also to have a chance to participate in the conference. We submitted an application in spring of 1986." (A. Turnbull, 1984)

❖ "I decided to apply for the IEEIR in 1983 when I was seeking international models to better understand how to develop home care for persons with severe physical disabilities in the United States." (A. Goldberg, 1983)

❖ "I believed that the mission of IEEIR was compatible with my professional goals. It gave me an opportunity to participate in an international project which I considered having benefit for the USA and take a leadership role (as either the first or one of the first fellows to visit a developing country) within IEEIR in redefining perceived geographic regions for exchanges. At the time of my proposal in 1982 there were serious questions raised by IEEIR regarding a visitation to India since prior protocol had been exchanges with western developed countries." (F. Bemak, 1984)

❖ "I decided to apply for an IEEIR grant when I received an invitation to give some presentations and do some consulting in New Zealand. I must admit that I had heard that the application process was rather arduous and that much was demanded of you upon your return, and that some people did not feel it was worth the aggravation. I decided to pursue, as I knew that IEEIR had a good reputation and that through IEEIR I could also avail myself of their very good contacts in the countries I wanted to visit. I enjoy writing and did not mind the requirement that I write a final report." (M. Backman, 1991)

❖ "I completed an IEEIR application during Spring 1992. I was motivated to complete the application by my desire to conduct research in Japan, and to be involved with an international organization devoted to discovering and exchanging information." (B. Wilhite, 1992)

Impact on Professional Life

Please indicate and comment on the extent the experience of the fellowship has influenced your professional life.

❖ "The Fellowship experience (1979) has to represent one of the highlights of my professional career. I have always considered myself a community psychologist dedicated to assisting clients/patients in fitting back into their community after they have suffered serious injury, illness or disease that has altered or even destroyed their previous goals/identities. By examining approaches transitionally my own perspective has been expanded." (L. Nielson, 1978)

❖ "In some major ways. The research has allowed me to take a better perspective on the role of cultural variables in assessing what is often thought to be neuropsychological syndromes. It has also allowed for much greater dialogue with colleagues internationally which I think is of extreme importance in new development in the field." (G. Prigatano, 1992)

❖ "Tremendous influence on professional life and on personal values." (M. Jansen, 1985)

❖ "The experience of the fellowship has had a major influence on my professional life. The information obtained has been incorporated into my teaching responsibilities and has been disseminated via conference presentations and publications. Also, the experience assisted in the development of contacts both in the United States, China, and other countries." (M. Condon, 1990)

❖ "I think that my fellowship experience in Hong Kong may have been unusual. First, I found that for a variety of complicated social and political reasons almost no attention was given to the problem with deaf children even though it was a matter of considerable concern with hearing children.

Second, during my stay I made the acquaintance of a number of fellow professionals who worked in the general area of language development of deaf children. But most have since migrated to other countries, e.g., Canada, Australia, the U.S., etc.

Third, these professionals became very interested in another related problem that I was working on, i.e., devising a computerized classroom language management system that could be used for all methods of teaching deaf children.

Finally, as a consequence of these events, I have been nominated for a Senior Fulbright by Macquarie University in Sydney, Australia. If that happens and if I also secure a grant from the Special Education Program of the U.S. Dept of Education, there is a good possibility that I can begin a sustained effort abroad for many years to come. This could also include Hong Kong because an old associate from Gallaudet University has replaced an Australian immigrant. (I will not know about the Fulbright until next month and the Ed. grant until June. So all of this remains highly speculative.)" (H. Bornstein, 1990)

❖ "The major influence was to appreciate the culture and living environment of the disabled person on the degree of handicap and the ability to cope and deal with it. Another influence was to open a world view of the disabled and their living circumstances to our medical and graduate students in orthopedics and rehabilitation. It confirmed that assistive technology rather than remediation is of equal importance in rehabilitation." (E. Bleck, 1989)

❖ "My professional life has been influenced quite a lot by my experience in Japan, and I have been influenced greatly in my personal life as well. I have found myself more open to the influences of other cultures, more sensitive to the ways in which culture influences individual choices, more concerned with the influence of culture on social service philosophies, and more concerned with the ways in which cultural difference affect both the philosophy and practice of service provision." (J. Myers, 1983)

❖ "The fellowship had a major influence on my professional life. It heightened my awareness of how powerfully cultural values influence decision-making in medicine (the high value, for example, placed on prevention and "normalization" in Sweden by contrast with the low value placed on these activities in the United States). It provided me with a better perspective on what is happening (or not happening) here in the United States. It influenced my teaching. And it also provided me with professional colleagues in both Britain and Sweden with whom I have maintained contact, in ways that benefit my professional (and personal) life." (J. Kugelmass, 1987)

❖ "The fellowship has been very influential in increasing my interest and commitment to collaboration with families and professionals in Latin America. This was greatly strengthened because of the interest that Mrs. Marianna Beach has in Latin America. Our Center is named for Mrs. Beach and she and her husband made an endowment to the Beach Center to have an ongoing collaborative relationship with the Inter-American Children's Institute in Montevideo, Uruguay. The fellowship was a catalyst for this ongoing collaborative work." (A. Turnbull, 1984)

❖ "The Fellowship experience was a major influence on my professional life. After returning from my Fellowship, I published my observations which led eventually to my promotion in academic medicine. In addition, I made many presentations at regional and national meetings. As a result of the response, I decided to return to Europe in 1986 as a Fellow of the World Health Organization to go into the issues in greater depth." (R. Smith, 1983)

Please explain how the experience of the fellowship has altered/influenced your professional life.

❖ "The experience of the fellowship has influenced my professional life substantially. It put me in touch with other professionals of national standing in the disability area; directly resulted in one national presentation and one journal article, and indirectly resulted in participation in an international conference and authorship of another journal article; and expanded my contact with NIDRR, from which I received two innovation grants (one in 1985 and one in 1991). My work in the area of my fellowship has dealt with policy." (S. Cohen, 1985)

❖ "The fellowship led to a major and unique opportunity: to develop a program for and at the World Health Organization (WHO) in Geneva. The "Initiative of Support to People Disabled by Mental Illness" is now a part of the official program of work of the Division of Mental Health. This professional experience led to the current position I hold." (M. Jansen, 1985)

❖ "It has affected the content of my teaching (curriculum development), and I also have continued professional contacts with Australian rehabilitation counselor educators. I am on the editorial review panel of the Bulletin of the Australian Society of Rehabilitation Counsellors, and I have been called on to review Australian faculty for promotion." (D. Hershenson, 1989)

❖ "IEEIR has had a significant impact on my professional work in the areas of program development, policy, and practice. Following the Fellowship I was identified as an individual having multicultural experience on an international basis. This led to extensive consultation, training, research and assistance in the USA policy development with regards to mental health issues relevant to refugees. My professional work in this area has continued and expanded to the Caribbean and Latin America." (F. Bemak, 1984)

❖ "The fellowship most influenced my professional life by giving me an incentive to develop a program plan in advocacy. For some time, I have been researching and writing a curriculum which will enhance the advocacy skills of people with disabilities. Having studied the Disabled Persons Assembly, which is consumer-led, I believe I have a better grasp of the issues important to people with disabilities." (A. Wasserstrom, 1989)

❖ "It was instrumental in the decision for a career change. I left my long-time teaching career to redirect my professional life toward consulting and research to seek answers about optimal rehabilitation interventions here and abroad." (C. Butler, 1991)

❖ "The concepts I gleaned have been shared nationally. My horizons have expanded considerably. My agency is reaping the benefits through increased international recognition. The area of greatest professional influence seems to be in practice where I am able to integrate and teach some of the strengths of the Japanese culture. It has been my pleasure to conduct several seminars on this topic and have had interest from professional magazine editors." (M. Cleary, 1992)

❖ "My experience in England in 1979 made me aware of their humanistic approaches in contrast to our professionalism in the U.S. It also provided the opportunity to network with other programs. Of particular interest at that time was the Institute for Sudden Deafness, something that we were never able to establish in the U.S.; but which we could apply conceptually to our local program. Also of interest was the program at Court Grange for emotionally ill, hearing impaired adolescents." (R. Green, 1979)

❖ "I often use examples from Australia when discussing approaches to service delivery. The programming I saw helped me to formulate a plan for an innovative service delivery project currently being funded by the U.S. Administration on Aging." (M. Bagley, 1991)

❖ "(a) *Curriculum development* The experience has supported the development and teaching of course work on culture and disability, e.g., a new course on the social and cultural contexts of disability, a course unit on cross-cultural and international rehabilitation. (b) *Research development* The fellowship has helped legitimize my professional interest in disability/rehabilitation in the country and region visited, and helped establish needed bases and credentials for future work there and elsewhere. (c) *Publications and papers* The study-visit has contributed to the preparation of one scholarly journal article and will contribute to other publications and presentations. (d) *Professional development* The experience has complemented my work as co-organizer of an international symposium on culture and disability." (J. Armstrong, 1992)

❖ "My principal concern was curriculum development during my study visit to New Zealand, and I find myself drawing upon the experience in every course I teach (master's and doctoral levels). I have also utilized my learning about New Zealand's social policy in subsequent efforts to effect disability policy." (M. Walker, 1989)

❖ "As a result of the fellowship, I have been contacted by several officials and professionals from Israel and have helped to arrange tours and visits in the United States so they could receive the benefit of seeing American programs and approaches and could give American legislators, professionals and researchers the benefit of their experience." (M. Kivitz, 1992)

❖ "Later in the year of my first grant, I travelled to Israel and taught rehabilitation policy at Haifa University. I could not have done a meaningful job of that teaching without first gaining the international perspective provided by my fellowship. While in Israel, the Lutheran Church financed the rehabilitation training, in Israel, of a large number of counselors from Africa and Asia. The University asked me to work with the group, most particularly because of my IEEIR fellowship. I learned a great deal about practice around the world from that teaching experience, and I hope I contributed to the dissemination of information to a significant audience. I have also used my increased knowledge in all my writings. Finally, I developed an understanding of the phenomena of international transfer of rehabilitation policy and practice through the auspice of multinational corporations which

I have discussed in many of my publications. For example, most recently I contributed a chapter on managing work force diversity to a book on the *American Edge* in manufacturing which can be directly attributed to thinking that started during my IEEIR fellowship." (S. Akabas, 1983)

❖ "I have become much more mindful of the importance of context in the design and delivery of services for individuals who need support in our society. I was reminded in Portugal of the importance and strength of a caring community, which cannot be replaced by advances in technology or social policy." (S. Hasazi, 1984)

❖ "The primary impact has been on deepening my understanding of the concept of "culture" and its impact on all aspects of life. Most specifically, it has broadened my recognition of the need to include cultural considerations in establishing public health and education programs and policies and in the training of professionals in all aspects of human services including education, health care and rehabilitation. In my own teaching and in-service work with special educators, a focus on the relationship between culture, disability, and healing has become more integrated.

The professional and personal relationships established with my host colleagues has had the most profound impact. I have become committed to the necessity of establishing a collegial relationship with a partner from the culture in which you are working in order to get a depth of understanding and adequate interpretations of information. Similarly, in development of new programs and policies, I've seen how "outsiders" can provide insights for programs that may be overlooked by those in the host culture." (J. Kugelmass, 1987)

❖ "The experience has helped to broaden my perspective and has enabled me to be part of an international network where we share information about research outcomes and practice ideas.

I have distributed my report at every opportunity, such as giving copies to physicians, teaching medical interns, giving presentations, workshops, and seminars at professional meetings to educate professionals about what I have learned in the area of patient-doctor communication.

Whenever possible, I try to effect policy. For example, I have shared my international experience via my report with the New York State Commissioner of Mental Health, Mental Retardation, and Alcoholism Services, as he has a special interest in communication between physicians and patients in a multi-cultural hospital setting. He is particularly interested in Interpreter Services, an area that I specifically investigated as part of my project. I was able to share with him information about a particular department in New Zealand that could serve as a model here." (M. Backman, 1991)

❖ "The actual experience was beneficial, and it continues to open professional doors for me. In particular, it has improved my knowledge base in rehabilitation, and strengthened my research skills." (B. Wilhite, 1992)

Outcomes and Benefits

What would you say are the two most important outcomes of your IEEIR visit?

❖ "The two most important outcomes of my IEEIR international visit were: (a) continuing my work in three additional countries in Western Europe at my own expense, and (b) providing the information I had collected to my colleagues in Colorado, across the U.S.A. and in Canada through publications of my report in two journals and through speaking engagements. A third invaluable outcome was the connection I had made with others in my field in the six countries I had visited. I was able to facilitate a visit to Denver for colleagues from Norway and Switzerland and to aid another in France in seeking a publisher for his book on treating children. I also helped two other colleagues in Holland with papers they were writing for American journals, which described their work." (S. Zimet, 1986)

❖ "Ever since that fellowship, functional assessment has been my continuing research and educational interest. Presently, the Functional Independence Measure (FIM) has gained widespread use in the United States and overseas and is likely to become the common language for describing disability throughout standard impatient medical rehabilitation programs. My exposure to the ICIDH/WHO model provided the needed rationale to understand the developments that lay ahead." (C. Granger, 1979)

❖ "The two most important outcomes were: 1) Ultimate writing of a book "Gait in Rehabilitation" and 2) Broader understanding of post graduate education and the advising of masters and doctoral students." (G. Smidt, 1979)

❖ "My ability to see how good international program ideas can be adapted to different national funding systems and philosophies. My Dutch colleagues have been impressed with the way in which I understood their culture and programming and described it in U.S. publications." (H. Versluys, 1983)

❖ "An important outcome of my international visit includes increased opportunities to host professionals in the field of blindness from Japan at my agency, the Carroll Center for the Blind. In addition, I have been invited back to Japan to address a nationwide conference in October 1993 on the topic of diabetes and blindness at the Konan Rehabilitation Center, with funding anticipated from the Japanese Ophthalmological Society." (M. Cleary, 1992)

❖ "The two most important outcomes of my IEEIR international visit are: (1) the cultural awareness I gained in New Zealand and how that affects the rehabilitation process, and (2) the friendships and professional exchange I continue with persons I met in New Zealand." (M. Walker, 1989)

❖ "Most important outcomes: (1) Habit of reading European and British journals. (2) Habit of seeking out British coworkers at international meetings." (N. Roberts, 1982)

❖ "As a result of the fellowship visit I have developed several lasting contacts and friendships. We continue to be of mutual assistance. I have been able to sincerely recommend that several researchers, whom I regard highly, make applications for projects that are important to them." (M. Kivitz, 1992)

❖ "The two most important outcomes are: 1) Understanding the differences of two cultures despite the similarities of these cultures. 2) Establishing an international network of professionals interested in issues of disability." (M. Logigian, 1986)

❖ "The opportunity to share with other professionals. Hopefully, my participation in workshops as guest speaker, and article writing, has inspired other rehab professionals to incorporate some of the Swedish philosophy and programming into their own practice.

N. Y. State OVR approved a new service for deaf clients as a result of my recommendation. Sign language classes at the work site of a deaf person are now paid for by the state and provided by cooperating agencies. This has proven to be an important part of job satisfaction, adjustment and retention for many deaf people." (J. Smith-Heisler-Loza, 1980)

❖ "As stated in the previous question, one of the important outcomes of my IEEIR visit was a greater awareness of the ways in which the cultural roots of society play a role in attitudes and practices concerning disability. A second major outcome was the comprehensive report of my three-week study visit to China that I submitted to IEEIR and which, I understand, has been useful to other fellows." (B. Wright, 1988)

❖ "My IEEIR study-visit involved the observation of a children's cochlear implant program in Sydney, Australia. During this visit, I was also able to work with the host institutes to design tests for young hearing-impaired children, and to test six of the first young children with cochlear implants.

The two most important outcomes were the personal observation of children with cochlear implants in an intense oral rehabilitation setting, and the ability to share the success of these children in publications and presentations around the USA and in other countries. (R. Tyler, 1989)

❖ "The first important outcome is an ongoing interest and commitment to working in Latin America and an increased recognition of how much the services within the United States can benefit from openness to learning best practices from other area. Secondly, I learned a great deal from my involvement in helping to plan and implement the Wingspread Conference on Cross-Cultural Family Support which was held in 1988. At this conference, representatives from ten different countries participated in sharing family issues and engaging in discussion concerning comparisons and contrasts. I found it to be a very stimulating and helpful experience." (A. Turnbull, 1984)

Do you anticipate any future outcomes? If so, please describe.

❖ "I have viewed the experience as a dynamic one which continues to drive me to consider new or altered ideas. Presently working on a self-contained half-way house for patients with limited support systems who are considered medically ready to return to the community. Quite often these people have been set up to fail because of the lack of alternatives." (L. Nielson, 1978)

❖ "I anticipate development of an international rural psychosocial rehabilitation network." (D. Dunlap, 1989)

❖ "Will be presenting research to international leprosy convention in September, publishing results, as well." (T. Brown, 1992)

❖ "My hope is that I will be able to apply social and economic principles learned through my study visit to rehabilitation problems in this country. In particular, the importance of community involvement and meaningful work are tenets I hope to see develop in this country." (M. Walker, 1989)

❖ "As I continue to grow in my field, I expect to have wider influence both on policy and research, and as a teacher. To the extent that the fellowship contributed to my professional growth, its influence will continue to be felt in the work I do in the years ahead. As an example, I (and three colleagues) have just edited a book in which ethical issues in perinatology are addressed." (J. Kugelmass, 1987)

❖ "Future outcomes are anticipated because of ongoing applied and comparative research. A current research project involves working with colleagues at the Rehabilitation Research Centre, Turku, Finland on a follow-up study of heart patients in order to assess the influence of medical & rehabilitation services, along with community and familial supports, on recovery. In addition, a comparative study is expected to be undertaken in the United States, using the same kind of patients and conducting the same kind of follow-up." (R. Smith, 1983)

Please comment on the overall benefits of overseas short-term study visits.

❖ "I felt that the two weeks in each country provided me with a wealth of information beyond what I initially expected to gain. The process of collecting and recording this information required careful preplanning and total immersion in the project once I was there. There was no excess time. For example, it was important that I took into account local holidays in order to maximize my time in setting up my visits." (S. Zimet, 1986)

❖ "I wonder just how beneficial a short term contact would be. In a new culture it takes time to "enter the culture", to see how to "conduct business" to sort through the surface layers to understand their policies and philosophy, their funding methods. It is complex and to really get accurate information would take longer, I feel.

I was fortunate because I had lived in Holland, my husband was Dutch and I was able to continue my contacts for at least 6 weeks each summer. My husband who was working there checked up when I felt there had been misunderstanding. Even then it took me some time to understand just how Dutch law worked in tandem with other systems. To arrange meetings.

It would be difficult to understand the unique and sometimes hidden features of a culture including their policies and philosophy and what drives their services without the time to ask questions, to clarify responses, to check-back and so on.

I think that a short-term visit would be beneficial only if the fellow had an interpreter who could be helpful, was able to prepare with readings and discussions and could find some way to check back to verify information and to ask more questions." (H. Versluys, 1983)

❖ "It was an altogether wonderful experience. I met many dedicated professionals, learned about their problems and solutions, wondered at why they did certain things and asked myself the same about some of our practices at home. I learned much even in a short visit. Perhaps, the most beneficial aspect is that the issues and people become "real" for you and you are more likely to continue interaction with them over the future years." (C. Butler, 1991)

❖ "Key benefits apart from the tangible is the intangible benefit of enhanced mutual international understanding." (G. Smidt, 1979)

❖ "Short-term visits are excellent opportunities. They must be preceded either by long-term pre-visits or extensive preparation prior to the short-term visit." (M. Condon, 1990)

❖ "Overseas short-term visits probably have the most effect upon younger individuals without previous international experience." (N. Roberts, 1982)

❖ "When well planned, and with a plan to integrate the experience with future endeavors, the benefit is great." (D. Dunlap, 1989)

❖ "I stayed for almost 3 months. I really feel that for my project any shorter stay would have been much less beneficial. For projects of a different type, shorter visits probably would be adequate." (D. Hershenson, 1989)

❖ "This trip certainly broadened my horizons! The world outside my city, state, and country is more real and less "alien." It is also less threatening and more friendly. It has also given me a "place" to go to get a different perspective on the familiar that is taken for granted." (M. Bagley, 1991)

❖ "As I review the fellowship reports and monographs (not to mention my own experience), I am impressed with how significant the studies were in shaping rehabilitation policy and practice. I believe the IEEIR exercised splendid judgement in selecting fellows and dissemination modes. For me, the overseas short-term visit brought me into contact with colleagues and concerns to last a lifetime." (M. Walker, 1989)

❖ "I believe that the benefits are enormous. It is incredible how much you can learn in a short-time. You can prepare yourself through reading and talking to others before you go, but I also found that much of what I experienced while there, "jelled" upon my return home, when I had a chance to think about it. Now whatever I read or hear about that part of the world has so much more meaning to me.

In a short-term visit you can get a very good feel about a culture and its people that can help you in your international perspective and dealings with those from other cultures here in the United States.

On a practical side, a short term visit is helpful as you are not away from your professional work here in the U.S. It is also less of a burden upon your hosts. On the other hand, during a short term visit they probably spend more intensive time with you than they might should you be on a longer visit. This is good for you but may be disruptive to them. (I must say though I was never made to feel that I was disruptive to anyone, and in fact was greeted quite warmly and with much cooperation.) (M. Backman, 1991)

❖ "The overall benefits of these short term visits are enormous if the fellow and sponsor are well prepared. They are practical for leaving your job for a short time. The benefits are the freedom to interact with scholars and clinicians in great depth, away from the day to day obligations of everyday life in your home setting." (R. Tyler, 1989)

❖ "In order to benefit from a short term visit to another culture, the visitor must either be familiar with that culture or be VERY focussed in the questions that he/she asks. Moreover, the less familiar with the setting the visitor is, the more responsibility falls upon the host. An enthusiastic, experienced host is probably necessary for a first-time visitor to learn very much. A more experienced visitor is more able to deal with other circumstances." (P. Ginsberg, 1992)

❖ "In my case, the short-term visit was most useful. Its richness was the result of the cooperation of the Chinese authorities, who provided a guide, translator, and chauffeur throughout my visit, and who arranged a great variety of institutions that I could visit — including hospital, employment, and educational settings. The professionals and other personnel at these settings were not only most cordial, but were eager to raise questions and engage in discussion about my observations." (B. Wright, 1988)

❖ "The overall benefits of overseas short-term visits allows a person to establish (or further) direct contact with others working on similar problems and at the same time permits one to gather more detailed information while on location. Both aspects facilitate further communication and exchange of ideas/information subsequently - an ongoing, two-way process of communication is enhanced by this kind of visit." (R. Smith, 1983)

❖ "The benefits of overseas short-term visits are that they broaden our perspectives and keep us humble too." (G. Gustason, 1987)

❖ "Quite beneficial when fellow has some prior knowledge/ experience in the chosen country, and has something of value to exchange." (B. Wilhite, 1992)

Other IEEIR Benefits

Have any of the IEEIR monographs, fellowship reports or other publications been useful to you in your career? Please explain briefly which ones and how you have used them?

❖ "I was very pleased to read the Interchange on Culture and Disability in the Pacific. Also the Project Director, Diane Woods, kindly sent me information from her files on rehabilitation in Japan which I found helpful. I look forward to receiving the refreshing monographs." (M. Cleary, 1992)

❖ "Several monographs have been used as readings in my courses. One in particular is important relative to the policy approach in other countries re: accessibility — Barrier Free and Safe Environments." (M. Condon, 1990)

❖ "Several fellowship reports have been useful in my work. Vic Finkelstein's *Attitudes & Disabled People*, Joe Stubbins's *Clinical Attitudes in Rehabilitation, a Cross Cultural View*, and Dr. Elizabeth Zucman's *Childhood Disability in the Family*. I arranged to visit with Dr. Zucman when I was in Paris. She in turn arranged for me to visit a program for hearing-impaired children where I saw the prototype of the IBM Speechviewer. I was able to follow up on that and ultimately obtain the equipment for the New York League for the Hard of Hearing. The fellowship reports of Harry Levitt, Irving Hochberg and Mark Ross were all useful in my work. Most recently, the monograph *Changing Views of Disability in Developing Countries* made me more aware of what was happening in 3rd World countries."
(R. Green, 1979)

❖ "As I mentioned earlier, I believe the IEEIR monographs are pace-setting and have used them extensively in my teaching. Among the ones I use most frequently are Purtillo (Humane Health Values), Finkelstein (Attitudes Toward Disabled), Wrightson and Pope (Barrier Free to Safe Environments), and Cornes (The Future of Work), Young (Low Birth Weight Babies and Ethics). I circulate the monographs within courses to raise student awareness of critical issues." (M. Walker, 1989)

❖ "Many of the IEEIR monographs provided background information and helped to structure my project in Israel. I also use the monographs to provide information concerning aging, employment, residential care, cultural diversity related to services for disabled individuals, etc. *Interchange* is also very helpful in summarizing studies and making us aware of activities, services and approaches in other countries." (M. Kivitz, 1992)

❖ "The Doug Biklen report on facilitated communication attracted my interest. As a result I wrote to him, read his article in the Harvard Educational Review on this topic, bought his videotape on facilitated communication, and have been teaching my students about it." (S. Cohen, 1985)

❖ "I have read many IEEIR publication with interest, particularly those on Australian rehabilitation that were useful in planning my fellowship activities. Other IEEIR monographs have also provided broader perspective to my teaching." (D. Hershenson, 1989)

❖ "Yes, I sent the aphasia in SE Asia monograph #45 to a neurologist in Thailand, who was interested in this topic." (T. Brown, 1992)

❖ "I always scan the IEEIR monographs. I am sure that an idea generated here and there becomes part of my general knowledge and outlook concerning other countries as well as the United States." (B. Wright, 1988)

❖ "I have benefited from the newsletter and from all fellowship reports that I have received. I have also benefited from the monograph, The U.S. Role in International Disability Issues. I have used these materials in writing and presenting current research, and in planning future research." (B. Wilhite, 1992)

International Network

How do you stay current on international advances in your field? Are you part of an informal or formal network?

❖ "Considerable informal networking with American and international colleagues in a variety of academic and applied fields. Formal networking through Society for Disability Studies, Disability Research Interest Group of the American Anthropological Association, IEEIR, etc. IEEIR publications; publications from countries of interest; UN publications." (J. Armstrong, 1992)

❖ "I am a part of an informal network and stay current on international advances by mostly reading. Also contact with colleagues." (G. Gustason, 1987)

❖ "By attending conferences and/or sessions at conferences with an international focus; through scholarly reading; through international contacts. I am not part of an informal or formal network of experts in my field." (B. Wilhite, 1992)

❖ "I have created a network regarding deafness in Poland." (R. Nash, 1983)

❖ "Work regularly with OAS." (R. Turnbull, 1984)

❖ "World Congress every 3 years and ISPO International Journal 3 times a year." (M. LeBlanc, 1986)

❖ "I stay current in my field by reading journals and corresponding with a very limited number of individuals through an informal network." (A. Wasserstrom, 1989)

❖ "Since my retirement I have gotten most of my current information on the elderly and the aging from regular reading of Aging International and Network News (a newsletter of the global linking for middle and older women) published by the International Federation on Aging (IFA) -Washington, DC." (E. Rudd, 1987)

❖ "I have several personal and professional acquaintances overseas and we have started a network." (C. Granger, 1979)

❖ "A) Reading B) Trips C) Informal Network"
(H. Wallace, 1991)

❖ "I don't very well. I take Disability and Rehabilitation and monitor international references. I also exchange reprints with some foreign colleagues." (R. Keith, 1987)

❖ "Besides the IEEIR publications, as a member of the social commission of Rehabilitation International, I receive publications bearing on the international scene from RI. I also correspond with foreign scholars in my field of Rehabilitation Psychology." (B. Wright, 1988)

❖ "Publications of WHO, international and domestic sections of Hospital and Community Psychiatry, publications of the NY State Office of Mental Health, conference attendance and participation, and informal discussions — especially those at conferences are particularly helpful." (P. Ginsberg, 1992)

❖ "I have developed working relationships with five professionals in Australia. Three have been here to visit our facilities. I have just hired one who will come here and work with me on a grant for the next 2 1/2 years. An informal network is usually established at international meetings, of which I am a part."
(R. Tyler, 1989)

❖ "Membership and attendance at meetings of International Rehabilitation Medical Association and International Congress of Rehabilitation Medicine." (T. Anderson, 1983)

❖ "Reading, as editor and associate editor of several journals I review a great many papers. I regularly use my modem at home to do Medline literature searches via the Stanford Melvyl system. I also subscribed to Knowledge Index, Dialogue, for literature searches in Medline dating from 1966. I attend many meetings as visiting professor. In 1991-92 I went around the world as President of the American Orthopedic Association—New Zealand, So. Africa, Egypt, England, France, Spain and Portugal. There was a lot to absorb. Due to my position I suppose I am a member of a formal network of experts. I am sent yearly the Status of the World's Children, UNICEP. This is loaded with data and used it as a framework for an editorial. Draft enclosed." (E. Bleck, 1989)

❖ "I have retained many of my former contacts as ongoing relationships and have thus been able to understand how the Dutch approach to rehabilitation has had to change to accommodate to realities of the 1985 through 1990's. This summer I updated my information on the status of many of my former study sites and a great deal has changed in the way in which the government views and funds services for children, the parent, and mental vs. physical disability." (H. Versluys, 1983)

❖ "International journals in addition to informal network of experts." (C. Berrol, 1987)

❖ "I subscribe to Worldwatch for International Information and read current advances as reported generally in newspapers and magazines." (P. Dvonch, 1984)

❖ "Remain in contact with the people I met in Australia. Also, look more carefully at items in newsletters, conference presentations, etc. regarding international activities. Part of an informal network in the U.S. of people in contact with professionals in Australia or who have been to Australia. IEEIR Newsletters."
(M. Bagley, 1991)

❖ "I stay current on international advances in the field through my activities with AAMR, my relationship to IEEIR and its materials, my position as executive direction of International Association of Jewish Vocational Services and informal as well as formal contacts with professionals in other countries."
(M. Kivitz, 1992)

❖ "I kept up with international advances in relation to child abuse and neglect, which was part of my fellowship focus,

through membership in the International Society for Child Abuse and Neglect." (S. Cohen, 1985)

❖ "*Formal*: 1) International Conference of Physiotherapists in Juvenile Arthritis. 2) World Federation of Occupational Therapists. 3) Arthritis Health Professionals Associations. 4) International Journal of Rehabilitation Research

Informal: Networking with colleagues, Reading journals addressing international activities" (M. Logigian, 1986)

❖ "I was one of the original members of the International Affairs Committee of the American Academy for Cerebral Palsy and Developmental Medicine which began in 1983 and later served as its chairperson. I have been involved in planning and implementing symposia, an instructional course and other informational formats for the members of our Academy. This is a relatively new activity for the Academy and for me, however. We have communicated with groups around the world about shared activities and I have read newsletters and other periodicals that came my way." (C. Butler, 1991)

❖ "I don't. IEEIR and the ACA International Committee Newsletters are my primary sources of information, plus occasional contact with an international aging organization." (J. Myers, 1983)

❖ "By reading, attending conferences, and by membership in organizations such as the Society for Health and Human Values and the Hastings Center, and through the visiting scholars who come to the Stanford University Center for Biomedical Ethics." (E. Young)

❖ "Stayed current by going back to Sweden/Denmark in 1992 and 1993. I am part of a formal network with colleagues in both countries." (B. Raschko, 1986)

❖ "I have joined the Division for International Special Education Services (DISES) of the Council for Exceptional Children. I read their newsletter. Also, have attended the international conference of the International Society for the Study of Behavioral Development." (J. Kugelmass, 1987)

❖ "I do have some colleagues in several foreign countries that I maintain periodic contact with; however I rely more on your periodicals and my monthly visit to the University of Utah library." (L. Nielson, 1978)

❖ "Conferences, networking and reading" (J. Strully, 1992)

❖ "My IEEIR newsletters have been invaluable to me in keeping me in touch with the international community. I am also a member of the International Division of the Council for Exceptional Children and receive newsletters from this organization as well. Finally, I utilize an informal network of colleagues from the U.S., Australia, and Europe to keep me informed."

❖ "I receive the British publication "The Conductor," the quarterly magazine of the Foundation for Conductive Education. I also receive the Hong Kong Physiotherapy Journal and the Pediatric Newsletter of the Canadian Physiotherapy Association. All the above have had recent articles on C.E." (M. Marx, 1988)

❖ "In addition to the IEEIR publications and other materials sent to me by Diane Woods, I attempt to keep up with international advances in my field through yearly literature searches of the journals. The International Journal of Partial Hospitalization was one such resource but it is no longer being published. Another resource are the people I met during my IEEIR fellowship. For several years following my data collection in the Netherlands, I had an active correspondence with my sponsor and one of the staff psychologists, reading their manuscripts and commenting on them." (S. Zimet, 1986)

❖ "I stay current primarily through reading professional journals, conducting research, and attending professional meetings." (G. Smidt, 1979)

❖ "Mostly through international journals and publications." (C. Lam, 1992)

❖ "Informal and formal networks. I am the Chair of the Health Committee for the Maryland-Rio de Janeiro Partners of the Americas program and on the Board of Directors. As an alumni of the Kellogg Foundation Fellows program I receive newsletters and information as well as correspondence from my colleagues. Also I maintain contact with the International Divisions with the American Psychological Association and the American Counseling Association and am viewed as a resource in this area." (F. Bemak, 1984)

❖ "I stay current through personal contacts and my own personal/professional network, including Xmas cards and a newsletter that I circulate." (R. Liberman, 1991)

❖ "Access to published materials available through the university and through computer linked literature files at other locations permit one to keep abreast of international activities in the field. Furthermore, having extensive contacts with government and non-government agencies, developed over the years, allows access to current information in their international arena. As a general rule, one acquires an informal network of contacts and to some extent this constitutes the core of a formal network of experts." (R. Smith, 1983)

❖ "I do find it hard to stay current regarding international advances in the field of psychology in rehabilitation. I read journals, contacts from abroad occasionally send articles, journals, etc. In the areas of post-polio syndrome in which I am active, I obtain useful information from the *Polio Network News* and *G.I.N.I.*" (M. Backman, 1991)

❖ "Remaining current is always a challenge and time intensive. I am a member of the following associations and attend their meetings furthering contacts with professionals with international interests: International Association of Special Education, Div. of International Affairs of the Council for Exceptional Children, and the International Affairs Association affiliated with the American Speech-Language-Hearing Association. In addition, I attend the meetings of the Kentucky Council on International Education. Informal networks include contacts

with professionals via mail and discussions with Fulbright scholars visiting my campus as well as those returning from Fulbright experiences." (M. Condon, 1990)

◆ "It is my desire to stay current on international advances in my field. I participate in a special interest group on International Diabetes Education and another in Blindness Rehabilitation." (M. Cleary, 1992)

◆ "Through friendships with colleagues in China and Norway; journal literature especially *Second Opinion* for example. No, I am not part of a network." (S. Govig, 1992)

◆ "I stay current on international advances in my field by travel. I am about to travel to France where I will be co-secretary of a meeting on home mechanical ventilation. This is one outcome of my Fellowship since my study directors are the president and secretary of this meeting." (A. Goldberg, 1983)

◆ "I primarily try to stay somewhat current through an informal network of friends in other countries and through the ongoing Beach Center collaborative work with the Inter-American Children's Institute." (A. Turnbull, 1984)

◆ "Primarily IEEIR newsletter and being an officer in the International Academy for Research in Learning Disabilities." (P. Gerber, 1984)

◆ "I am part of an informal network of British and German teachers of rheumatology interested in teaching rheumatology via interactive computer systems." (N. Roberts, 1982)

◆ "I stay current on international advances through an informal network, through correspondence, journals, and publications from England and Australia and IEEIR." (R. Green, 1979)

◆ "I receive newsletters, copies of national journals, and other books and articles. I am on the list of approved grant reviewers with the Rehabilitation Service Administration in Washington, DC." (A. Dickerson, 1983)

◆ "I regularly read the IEEIR newsletters and the Australian professional journal Bulletin of the Australian Society of Rehabilitation Counsellors." (D. Hershenson, 1989)

◆ "This is difficult. There is no single way in which I am able to do this." (G. Prigatano, 1992)

◆ "By way of membership in the IAPSRS and the WAPR and of course — the IEEIR project." (D. Dunlap, 1989)

◆ "I don't stay current with international advances." (C. Vash, 1984)

◆ "I maintain contact with a number of professionals in Asia and Europe. As best I can tell, the US spends a great deal more money and makes greater progress in the area of deafness than other countries." (H. Bornstein, 1990)

◆ "Journal reading. No formal networks." (K. Garnett, 1984)

◆ "I receive publications from the National Association of the Deaf, and the newspaper called Silent News. Both carry international news on deafness. I receive some publications concerning deafness activities in Sweden, and I am in correspondence with a Swedish woman who is employed in deafness rehab programs there. She keeps me informed of current trends and activities. I also receive a weekly Swedish/American newspaper." (J. Loza, 1980)

◆ "My informal network in the field of international rehabilitation is much better than my formal network. Thanks to Diane Woods, I stay informed about conferences and monographs. I subscribe to Rehabilitation International, and that also keeps me in the information flow." (M. Walker, 1989)

One of the uses the IEEIR is thinking about making of this study is to make recommendations for a network of international resources for the mutual benefit of U.S. and foreign disability specialists. Some ideas include a loose-leaf directory of resources abroad and an electronic mail network. (a) In your view, would a formalized network be beneficial? To whom and how? (b) What role do you see yourself playing in an international network of experts in the disability field?

◆ "Disability/rehabilitation "profiles" of countries visited would perhaps be useful. I would anticipate being a contributor and user of the resources." (J. Armstrong, 1992)

◆ "I think IEEIR could be very helpful in establishing a network of international resources. In my mind, the Disability Studies Quarterly does a fine job of highlighting upcoming events and items of interest. Perhaps it could be a model for communication of international items. I would also like to participate in an electronic mail network, and would see my role as a rehabilitation educator/researcher." (M. Walker, 1989)

◆ "A formalized network could be extremely beneficial for the sharing of information about rehabilitation. Many of the professionals abroad are hungry for such information but cannot afford the dues or subscription fees. A low cost system of disseminating information would be an answer to their dreams. I would be happy to provide any assistance possible to establish this network. I am certain that AAMR and IAJVS could be counted upon to cooperate in establishing such a project." (M. Kivitz, 1992)

◆ "I believe that a formalized network should be tested first to determine to what extent it would be used. It might be useful to determine if there is already such a network in existence for another group and find out how effective it is for them. Are there such networks already in existence through the organizations already representing specific disability groups? Perhaps, collaboration with these groups in setting something up would make sense so that there is not a duplication of effort. I recommended such a network to the American Association of Partial Hospitalization several years ago in my keynote address to them. I don't believe they picked up on that idea as yet. I think it could

be an effective tool in alerting people to critical issues for large scale action (contacting legislators, etc.) and in sharing ideas and recent developments across the world. I would be willing to assist in examining the issues I raised and in working towards the implementation of such a project should it be deemed useful." (S. Zimet, 1986)

◆ "I think that a directory of major centers, programs, and resources in the disability field would be very useful. I'm not sure that a new, formal network is needed, but some kind of loose affiliation with existing national and cross-national networks might be valuable. I would not be able to play a major role in any international network but I would be interested in participating in some conferences, some meetings with overseas visitors to the US, and perhaps some written exchanges." (S. Cohen, 1985)

◆ "a) Formalized network would be beneficial if information can be current. An every-other-year conference to discuss appropriate issues would be most useful, i.e. a conference devoted to one topic, in depth. b) I would like to be an active participant in an international network of experts in the disability field. I would enjoy writing for a journal, presenting a talk, helping to organize a conference." (M. Logigian, 1986)

◆ "Yes, definitely! It would benefit both specialists here and abroad. My study/travel project was looking for innovative ideas in the care of children with disability that could be shared with others. I found there to be no lack of good ideas in addition to dedicated professionals. Most, however, work in isolation without knowledge of others who labor with the same issues nor do they have a forum for dissemination of information regionally, nationally or internationally. I came to believe that the most important innovation would be a means by which we could share our experiences with one another. It would benefit those in developing countries because many solutions they are formulating have more cultural and practical relevance than ones that were imported from developed countries. Those in developed countries benefit by having a different perspective from which to view the solutions we have derived and how to better share what we have learned. I do not currently have a vision of what my role in such a network will be, but I am committed to being involved in such an endeavor. I, personally, will continue to share information with the some 100 professionals and few parents I met during my study-travel project." (C. Butler, 1991)

◆ "I find that the informal networks are the best, however, some sort of central directory would be helpful." (J. Strully, 1992)

◆ "I am just beginning to use and explore E-mail. My university will install it on my computer within the next 4-6 weeks. I expect to have a steep learning curve, and anticipate that I will want to become part of a network if it is established. In the meantime, I do not believe I have enough experience here to be helpful. I believe we are part of a global society, and as such welcome the opportunity to dialogue, in all possible manners, with colleagues in other countries. I would enjoy being part of a network for information and idea exchange." (J. Myers, 1983)

◆ "(a) Yes, governmental and non-profit rehab agencies. E-mail is a very good means. (b) I can be a contact person or host for foreign scholars. Chicago has probably the best rehabilitation resources and facilities in the U.S." (C. Lam, 1992)

◆ "Think an international network of disability experts would be good. The whole area is sufficiently broad that subgroups would no doubt be required to engender ongoing interest. I would be interested for example in a network that dealt with physical impairment/disability with respect to the workplace with particular emphasis on back pain; an important clinical problem in common with the international community." (G. Smidt, 1979)

◆ "I am not familiar with what international networks are available these days. My current job involves public welfare reform, employment and training of public assistance recipients. In rehab, it seems as though links could develop between IEEIR and American Congress of Rehabilitation Medicine in a more active way. Would really like to see a link of IEEIR with Rehab in National Partners of the America's with Mexico, Central America and South America. Possible "Blended Funding" between Partners (RSA) and IEEIR." (H. Graden, 1979)

◆ "A network of international resources would be helpful — especially if they contained tables of contents, so each person could order the particular articles that are of special interest to them." (M. Marx, 1988)

◆ "I think an electronic mail network would be very useful. It would allow for easy access to individuals with common interests that otherwise might be unknown to one another. I would be willing to be included in such a network." (S. Hasazi, 1984)

◆ "Like the idea for a network of international resources. I have been somewhat of a contact point here in the inter-mountain West (Utah, Idaho, Wyoming and Nevada) for sharing this type of information. Your proposal would certainly expand my data base and provide more current information to others."
(L. Nielson, 1978)

◆ "Recommendations for a network of international resources for the mutual benefit of U.S. and foreign disability specialists. (a) A formalized network would be good if it is updated - people move and change positions. A list of FAX numbers is very necessary. (b) I serve as a guide and resource person to those interested in my areas. (b-2) Lead tours — am experienced. (b-3) It is a great help to have someone to assist in a million ways. (b-4) Make introductions and explore new areas. (b-5) Brief future researchers on methods and customs in certain countries. I am deeply interested in this project and am sorry that I am under a tight time schedule. I probably will have a lot more ideas when I return June 6th to share. IEEIR still has me on the go to learn about research begun in 1986 under your support."
(B. Raschko, 1986)

◆ "(a) A formalized network would be useful to those who have international experience and those wishing to find opportunities for international work. It would be useful to both an American audience and those abroad who wish to make connections with one another about their work and explore new collaborations. (b) I would be interested in connecting with others interested in services for children in other countries, sharing information,

resources and ideas." (J. Kugelmass, 1987)

❖ "(a) A formalized network of U.S. and foreign disability specialists could be beneficial to scholars, providing it does not become a lobbying organization driven by an ideology. Electronic mail would be the most appropriate way of linking us together, in my view. (b) My own role in the disability field will continue to be somewhat marginal. My work tends to be in the tertiary care setting, where acute decisions must be made. Others working in the long-term institutional and rehabilitative settings will have a more central role than me." (E. Young)

❖ "A formalized system of networking of disability specialists would be helpful to those who participate, by providing current information on trends and programs. I would be very happy to host deafness specialists from other countries. I feel I am in a position to help arrange meaningful contacts and visits in this country." (J. Loza, 1980)

❖ "I have not had much experience being part of formal networks. Typically, I have relied on my own informal network. I would certainly be open to exploring how a directory of resources would be helpful. I have not in the past used electronic mail, but I am realizing *the need to move into the 20th century!*" (A. Turnbull, 1984)

❖ "A formal network of international exchanges would be absolutely valuable. I believe it should list people by their interests and activities and would be highly utilized." (A. Goldberg, 1983)

❖ "Yes, I believe a formalized network would be beneficial. (1) I see both of the above organizations attempting to explore options individually. It would be helpful to have a guiding, coordinating network. I would be happy to participate in such a venture. (2) I am available as a liaison in matters of diabetes and vision impairment in people of Japanese origin." (M. Cleary, 1992)

❖ "A formalized network is needed as many associations in this country are relatively new in the field of special education and they are struggling and duplicating efforts. All of the above associations would be interested in my opinion of a clearinghouse of information or electronic mail bulletin board via SPECIAL NET OR BITNET. My role in an international network is perhaps information sharing and personnel preparation." (M. Condon, 1990)

❖ "I am not sure what a "formalized" network would entail. Resources that might be helpful would be: A directory of names, etc. and areas of specialization and interest; please include FAX numbers when available, as mentioned above. The possibility for receiving copies of publications that experts learn about or bring back from their visits abroad. I sent some of the literature to IEEIR when I came back in hopes that it might be shared with others, but I am not sure if IEEIR has the space or facility for storing or duplicating these articles and other publications. I also did not have the space for everything that I was given to bring back with me, so the idea that the expert should keep it is of limited value. A center or library is needed. I might have an occasional use for such a formalized network or resource center, but at the moment the current information provided by IEEIR has been quite helpful.

A resource of travel monies available to professionals that we meet abroad who would like to come to the U.S. would be useful. I was asked many times how someone could get a grant like I had and did not know what to tell them. Not to be greedy, but it would be nice if small travel grants were available to those who may have had a grant before. This would be to do follow-ups in the countries originally visited, or to continue the study in another culture. If IEEIR does not have the possibility for such monies, a resource guide of foundations, government agencies, etc. would be useful. Financial support is of particular concern to me as I am in private practice, and my institutional affiliations are part-time. Thus, I am not eligible for grants, etc. through the institutions. As for my role in an international network of experts, I am really not sure at this time." (M. Backman, 1991)

❖ "(a) If I were on an overseas sabbatical or leave, it would be beneficial to me by perhaps assisting research for publication and by stimulating or challenging my current opinions. (b) By being research person (as in a) for anyone interested in mutual concerns in an American context." (S. Govig, 1992)

❖ "A network of international resources" somehow suggests there might be available a pool of 'resources' that one can tap into and perhaps utilize for a particular purpose, e.g., funds and/or equipment. I presume 'resource' in the context you wish to use the term refers primarily to personnel - experts in the disability field - but not to other types of resources. If so, a more direct term should be considered, such as, a 'network of international experts'; or, if a broader meaning is intended - of 'international facilities and experts'. This phrase suggests that one may wish to be in contact with a particular agency, institute, university, etc., as well as individuals, directly involved in the field of disability and rehabilitation. Thus, a 'directory of resources abroad' should specify content and then figure out a way to develop such a resource tool. It could be beneficial to individual ' experts' and agencies working in the field (including individuals on specific lists, e.g., Am. Public Health Association's Caucus on Disablement interest group, ditto for sociology and psychology, and the wide array of agencies — public and private — concerned with this topic). This 'listing' is what one would have to tap into in order to 'advertise' the availability of such a directory. Certainly, one can advertise in the professional and trade journals (news bits inserted), newsletters of various agencies and groups, and via other means such as flyers and brochures. A 'directory' would have to be kept updated, on a routine basis, in order to serve the needs of those utilizing it as a resource tool. The electronic mail network would help in communication and facilitate the exchange of contacts and information in the network.

Individuals identified with this network would be able to play a vital role in promoting the exchange and dissemination of information related to the wide array of issues confronting disabled people in society, in cross-national settings. In general, it would broaden one's perspective and understanding of disability as it occurs in diverse cultural settings." (R. Smith, 1983)

◆ "(a) Yes but it would help if the network was categorized by disability areas such as mental health, developmental disabilities, vocational employment, etc. (b) I would like to contribute with the mental health aspect of the network to assist with the exchange of resources such as information about model programs, intervention strategies, or innovative prevention methodologies. I would also be willing to assist in the formation of a core group of international specialists to collaborate with international research activities, publications, assisting in defining national and international policy, and possibly facilitating individual exchanges and/or small group meetings." (F. Bemak, 1984)

◆ "As I indicated above, if I obtain additional financial support and if my computerized data base is as effective as I believe it could be, then I can see some great advantages in a formalized network to disseminate and compare research data."
(H. Bornstein, 1990)

◆ "Such a formalized resource would not be of any value to me; perhaps however to a governmental agency. I already have a role in my international activities; e.g., I am chairing a symposium at the annual meeting of the American Psychiatric Assn. in San Francisco, May, 1993, "International Dissemination of Skills Training for the Seriously Mentally Ill"— representatives from Poland, Norway, Japan and Switzerland will present." (R. Liberman, 1991)

◆ "I don't immediately imagine the benefit to me (and can't say for others) and see no role for me." (C. Vash, 1984)

◆ "(a) Yes - very beneficial for rehabilitation educators and researchers (b) among my roles could be forming or participating in (1) a network of rural- focused colleagues and (2) a network of rehabilitation educators interested in developing and promoting cross-cultural learning experiences for students."
(D. Dunlap, 1989)

◆ "(a) Yes. This would be especially useful for people who are involved in brain injury rehabilitation. This could be coordinated perhaps through the Institute on Disability. (b) I would be happy to provide information concerning our program in rehabilitating brain dysfunctional patients as well as sharing information concerning the assessment of these individuals."
(G. Prigatano, 1992)

◆ "A loose-leaf directory of resources would be very useful. I would welcome a world-wide directory of rehabilitation educators who have international interests and of rehabilitation counselor education programs. I believe that a network of educators and of educational programs would be to everyone's benefit in exchanging curriculum ideas and in finding out about solutions to similar problems that have worked elsewhere. I would be happy to help develop such a network and to participate actively in it. (Unfortunately, I do not have e-mail, so use of that medium would not be possible for me)." (D. Hershenson, 1989)

◆ "With the advances made in electronic mail, satellites and telephone it would be possible to develop an international network. It would be especially helpful if some method could be devised so third world countries could benefit. My recommendation would be to have a seat with United Nations or at least an access for getting information to other countries. A roster of interested professionals could be made available. I would be interested in such a venture." (A. Dickerson, 1983)

◆ "A formalized network would be most useful. For example, while at the League for the Hard of Hearing we saw consumers from other parts of the world. It was extremely helpful to have resource information including names and addresses to share. It provided some of that humanistic approach which I saw emphasized in England." (R. Green, 1979)

◆ "(a) I am uncertain if a formalized network would be beneficial (b) Evaluation of drivers with arthritis is my major area of rehabilitation expertise other than cost-effectiveness studies."
(N. Roberts, 1982)

◆ "(a) Yes. Past fellows (b) Very little if it does not involve learning disabilities and employment/disability issues."
(P. Gerber, 1984)

◆ "I think a network would be wonderful. However, HKNC would not be able to access a computerized network. We do not have the hard or software necessary. I would love a way to give and get information both general information and to ask and even answer specific questions about program and practices. I currently have on my desk a specific inquiry from a contact I made in Australia." (M. Bagley, 1991)

◆ "(a) Yes, extremely beneficial to me as it would provide a useful reference for obtaining information and for remaining in touch with professionals and organizations internationally. (b) Obtaining and providing information; arranging site visits; arranging for technology transfer as part of my official duties."
(M. Jansen, 1985)

◆ "I can see (a) as beneficial to educators, writers, overseas practitioners. I must admit I don't see myself as being too useful in (b) sorry!" (P. Dvonch, 1984)

◆ "I think a formalized network would be useful for those interested in projects or collaboration with colleagues abroad. A researcher might identify useful data that could be plugged into his/her own work and not have to "reinvent the wheel". I'm not certain where I would fit into this network, since as a dance/movement therapist, I remain on the fringe of the rehabilitation community. Notwithstanding, I do think it would be of service to many rehabilitation specialists around the globe, providing instant access through electronic linking." (C. Berrol, 1987)

◆ "The ideas for a formalized network would be beneficial. Despite my interest in this area I have, right now, limited time to devote to international studies. This may change in a few years."
(H. Versluys, 1983)

◆ "I think it a good idea and I would be pleased to be a beneficiary of such a system and where appropriate contribute to it." (A. Gartner. 1985)

❖ "Network of international resources. Might be a good idea providing you have a good computer data base. The American Orthopedic Association has founded the International Center for Orthopedic Education at our offices in Rosemont, IL (O'Hare Airport area). We have purchased a computer system. The intent is to have us act as a "broker" for physicians from the USA to find opportunities to visit other countries as short and medium term fellows and for orthopedists from other countries to visit us in the same capacity. We hosted in San Francisco, November 12-15, 1992 an invited international meeting on defining this need. Some 80 people from 40 countries participated and enthusiastically endorsed the idea. If you want a report of this meeting, you may write: Hildegard A. Weiler, American Orthopedic Association, 6300 N. River Road, Suite 300, Rosemont, IL 60018-4263. I think this should be ready in February." (H. Bleck, 1989)

❖ "(a) Yes, beneficial to rehab professionals all over the world. (b) Advisory only since I am retired." (T. Anderson, 1983)

❖ "I think the formal network is potentially useful. For developing nations, an electronic mail network is not yet viable in many places. (e.g., Kenya does not have this capability as yet.) For this reason, a loose leaf notebook will be more useful—perhaps with annual or 2 to 3 year updates. This way, travellers would know who they might contact while abroad or to whom they could write for specific information. My own role would likely be simply that of one of the persons listed. I would contact others if I intended to travel or if I wanted information in their specialty area. I would be happy to help others who contacted me with similar needs." (P. Ginsberg, 1992)

❖ "(a) It is difficult for me to judge if such a network would be valuable. I suppose it might be valuable to me if I were going to a country where few people participated in international meetings (e.g., China), and I wanted to know who I could meet in a particular town. (b) I would be happy to be on a list of potential visit sites in the USA." (R. Tyler, 1989)

❖ "Formalized network would be beneficial for faculty, staff, students. I would be glad to help." (H. Wallace, 1991)

❖ "(a) A formalized network would probably be beneficial, although I don't have any bright ideas regarding "to whom and how." (b) I do know that I have ideas concerning attitudes and stereotyping in general that are useful in counteracting prejudice and devaluation concerning people with disabilities in particular. These ideas are based on a number of basic concepts that have been empirically supported. Of course, I would be glad to share these ideas and apply them to concrete situations as presented by experts in the disability field." (B. Wright, 1988)

❖ "This might help my insularity and that of many in the field. I'm not sure what role I could play. Might provide manuscripts of work in press or in progress. A worthy endeavor." (R. Keith, 1987)

❖ "I believe that a loose-leaf directory of resources abroad would be useful. A formalized network is beneficial in that one could easily identify a whole host of foreign disability specialists rather than the limited number of specialists involved in one overseas visit. I believe that I could do so much more with my fellowship (research and writing) if I had immediate access to a formalized network. In terms of my own role, I would correspond and share information with others in the disability field." (A. Wasserstrom, 1989)

❖ "(a) Yes, very helpful (b) Could be done in conjunction with ISPO (c) Could be useful for coordinating assistance to developing countries as well." (M. LeBlanc, 1986)

❖ "(a) Yes, to parents, professionals, people with disabilities (b) I will continue to participate in and supervise our Center's work with OAS." (R. Turnbull, 1984)

❖ "Useful only if kept current. Better, perhaps, to have a list of people who one can call to obtain names, advice, etc. Formal, detailed lists seldom stay current." (R. Nash, 1983)

❖ "If by resources you mean contact people and organizations, then I believe this type of formalized network would be quite helpful. It would be helpful to know the areas of interests and expertise of each contact/organization. In the future, I hope to become involved in promoting community awareness of and sensitivity to disability issues - in this country and abroad. I would like to be involved in grassroots social change." (B. Wilhite, 1992)

❖ "The idea of a network for international resources sounds good but our field of deafness is so small I'm not sure this would be of much help." (G. Gustason, 1987)

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